

Intensive Paediatric Case Finding: evaluation of a programme  
for identification of HIV positive children and adolescents,  
Dar es Salaam, Tanzania.

Dissertation in fulfilment for Masters of Philosophy in Palliative  
Medicine, University of Cape Town, South Africa

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## DECLARATION

I, Frank Manase (MNSFRA004), hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

**Signature:**

**Date:** 28/01/2014

Signed by candidate

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I dedicate this work to my late dear father Anamoo Manase. I ought to express my sincere gratitude to my wife Doris and my children Hanscom-Anamoo, Gail-Margreth, Gean-Evelyn and Franklin-Ben for their immeasurable moral support throughout the process of getting this work done. Special thanks go to my mother Margret Manase for devoting much of her time to taking care of our children at times when I and my wife had to be away from the family to get this work accomplished. I would like to thank my colleagues Dr. Alick Kayange, Sis. Joyce Iriya, Sis. Mery Mwalongo and Sis Lucy Maembe for their tireless engagement in both implementation and evaluation phases of the IPCF project. Also special thanks to my mentor Dr. Liz Gwyther for the great academic support. I also wish to thank the PASADA staff, the research participants, PASADA clients, the Tanzania Ministry of Health and Social Welfare, USAID, Gail Reiner, Karilyn Collin, Mary Ash, Gean Pruitts, Frank Dunhum, Kayus Mrina, George Chuwa, Neema Kitale, Hanscon Lucas, Daniel Manase, Charles Sloan, and Manase family for the support they gave that enabled accomplishment of this work.

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### III. Abstract

**Title:** Intensive Paediatric Case Finding (IPCF); evaluation of a PASADA programme for identification of HIV positive children and adolescents in Dar es Salaam, Tanzania.

**Background:** An estimated 390 000 worldwide new paediatric HIV infections occurred in 2010 alone. If these children do not have access to antiretroviral therapy, less than 25% of them would survive past the age of five years. Identification of HIV infected children is essential to provide comprehensive HIV care and treatment; however, only an estimated 15% of HIV exposed infants globally receive HIV testing in the first two months of life thus strategies to increase identification of HIV infected children are critically needed. PASADA, a non-profit organization based in Dar es Salaam, Tanzania, developed a programme to identify HIV infected children and adolescents named Intensified Paediatric Case Finding (IPCF) which utilized the existing community networks which include: health care providers, hospital visitors, friends, families and patients of the PASADA medical centre. The purpose of the study was to evaluate the impact of the IPCF in improving identification of HIV positive children. Contrary to other two traditional approaches for HIV testing, Voluntary Counselling and Testing (VCT) and Provider Initiated Counselling and Testing (PICT), the IPCF approach initiates the process of HIV testing for children by identifying children while at the community through utilization of community social networks whereas, VCT and PICT interventions initiate the process of HIV testing for children who have already presented at health facilities for either an HIV test or other health needs. Also IPCF uses unspoken social clues to identify children who are at higher risk of being exposed to HIV and it widens the scope of people who influence the process of HIV test in children without violating a legal obligation of primary caregivers to provide consent for an HIV test for children. **Specific AIMS:** (1) to determine the impact of IPCF intervention in identification of HIV positive children, (2) to determine perceptions of guardians on the IPCF and VCT approaches, (3) to assess experience of living with HIV among children living with HIV and their guardians, and (4) to compare characteristics of HIV positive children identified through IPCF and VCT approaches.

**Material and methods:** A prospective, cross-sectional descriptive study was conducted between January and April, 2011 and a total of 227 participants were recruited from PASADA clinics (IPCF=151 and VCT=76). The average age for children in the IPCF and VCT groups were 11.3(SD=3.5) and 12.6(SD 3.5) years respectively. We administered structured questionnaire in addition to a retrospective review of PASADA health records before and after IPCF began. Both Qualitative [focus group discussion] and quantitative [questionnaires] methods were used to collect the information. **Results:** There was no significant difference in CD4 count at the initial visit between IPCF and VCT clients, however over 33% of participants in each groups had CD4 < 200 cells per microliter. New enrolment increased at the beginning of the IPCF programme in January 2010 and showed sustained increases through July 2010 by 42% ( $p=0.001$ ). The study revealed that participants in the IPCF group were significantly more likely to have visited more providers prior to being diagnosed with HIV than VCT participants (46% vs. 31%, respectively;  $p=0.001$ ). **Conclusion:** IPCF provides a model for leveraging existing community structures to identify HIV-infected children who have previously been undiagnosed in the formal health sector. This model could be expanded in other settings to increase HIV testing and strengthen linkages to care for children. Efforts to expand IPCF to identify more children, especially those at earlier stages of disease progression, should be developed.

#### IV. Acronyms

<b>ARV</b>	Antiretroviral drugs
<b>ART</b>	Antiretroviral therapy
<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>CTC</b>	Care and Treatment Centre
<b>FGD</b>	Focus Group Discussion
<b>HBC</b>	Home-Based Care
<b>HDT</b>	Human Development Trust
<b>HIV</b>	Human Immune deficiency Virus
<b>HSHP</b>	Health Sector HIV and AIDS strategic Plan
<b>MUHAS</b>	Muhimbili University of Health and Allied Sciences
<b>MOHSW</b>	Ministry of Health and Social Welfare
<b>NACP</b>	National AIDS Control Programme
<b>NIMR</b>	National Institute of Medical Research
<b>OVC</b>	Orphans and Vulnerable Children
<b>PMTCT</b>	Prevention of Mother to Child HIV Transmission
<b>PASADA</b>	Pastoral Activities and Services for People with AIDS Dar-es-salaam Archdiocese
<b>PICT</b>	Provider Initiated Counselling and Testing
<b>PLHIV</b>	People living with HIV
<b>IPCF</b>	HIV Intensified Paediatric Case Finding
<b>TACAIDS</b>	Tanzania Commission for AIDS
<b>TB</b>	Pulmonary Tuberculosis
<b>TB/HIV</b>	Pulmonary Tuberculosis and HIV
<b>VCT</b>	Voluntary Counselling and Testing

## CHAPTER ONE: Introduction and Literature review.

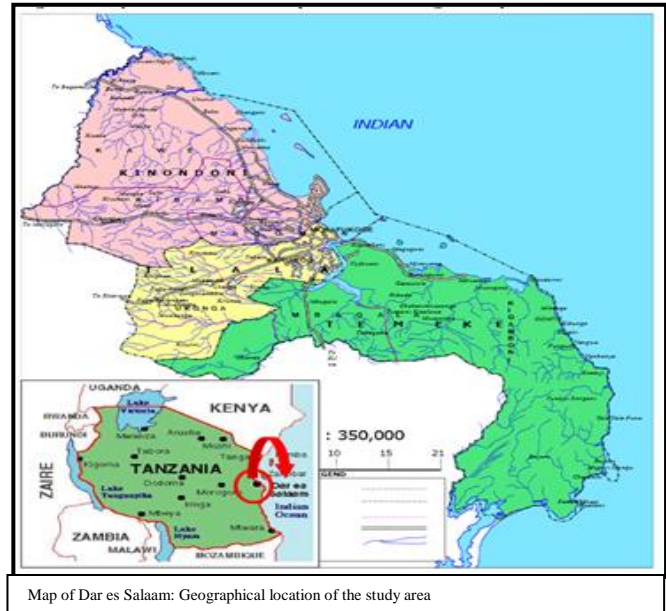
### 1.1.1. Background

A high prevalence of HIV in children has slowed down the progress to reduce child mortality in Sub Saharan Africa countries (Kellerman & Essajee, 2010). Global reports have shown that children account for 18% of HIV-related deaths and 15% of new HIV infections each year in Africa (Blasini et al, 2004:181). In 2007, UNAIDS estimated that approximately 6.2% of 33.4 million people living with HIV globally were children and over 90% of these infections in children were attributed to vertical transmission of HIV (UNAIDS, 2008a:37). Worldwide reports on the burden of HIV estimated AIDS to be the eighth leading cause of death among adolescents aged 15 to 19 years and the sixth leading cause of death among adolescents aged 10 to 14. However, in countries with high HIV prevalence, AIDS ranked much higher in the list of causes of death among adolescents (UNICEF, 2011:24). In Africa, the proportion of new HIV infections in children has remained high. In 2008 alone, of the estimated 2.7 million new HIV infections, 430 000 (16%) infections were in children. In 2009, two million of world-wide deaths were attributed to HIV and AIDS and 280 000 (14%) death occurred in children. In Sub Saharan Africa, HIV has caused more deaths than any other infectious diseases, having overtaken malaria and tuberculosis as cause of death (Matlin & Nancy, 2000). Lack of equality in laws of inheritance in Tanzania is a huge challenge and has particularly left women and children suffering especially in the light of AIDS pandemic (Tamar, 2011: 602-662).

Despite the tragedy depicted by these numbers, the current efforts have not provided much impact on the problem of HIV in children thus more needs to be done (Foster, 1997:82). Progress toward achieving the millennium development goal four (reduce child mortality) in many countries from Sub Sahara African has not promised to align with the expectations (Global Health Workforce Alliance, 2010), therefore review of traditional strategies to revert child mortality is critically needed.

Tanzania, East Africa has a population of 44, 928, 923 people with a 2.7% population growth rate. The country constitutes 25 regions, 20 being in the mainland and 5 in Zanzibar (National Bureau of Statistics, 2012). The prevalence of HIV in adults aged 15-49 years has been reported to decline from 6 percent to 5 percent between 2007 and 2012 (TACAIDS, 2013:109-111). Tanzania is among the countries worldwide hardest hit by HIV with high prevalence of HIV in children. According to the

United Nations (UN) report, Tanzania has reported a continuous increase in the number of children living with HIV from 38,000 people in 1990 to 230,000 in 2011 (Mundi Index, 2013). This is already a very high pace compared to many other countries worldwide. The government of Tanzania has strived improve access to HIV testing services for the citizens through various targeted interventions in collaboration with the



Map of Dar es Salaam: Geographical location of the study area

private and donor communities. In 2007, the president of Tanzania his excellence Dr. Jakaya Mrisho Kikwete launched a national HIV testing campaign as a strategy to roll-out HIV testing services in urban and rural areas (TACAIDS, 2007).

### 1.1.2 Counselling and testing

HIV voluntary counselling and testing (VCT) is a process by which an individual undergoes confidential counselling to learn about his/her HIV status and to exercise an informed choice in testing for HIV. The client must make the decision to pursue counselling and testing on his/her own free will on the basis of the information provided during the counselling session, i.e. an informed decision. The client also has the option to terminate or postpone participation at any point in the process (NACP, 2005a:102). Provider Initiated Counselling and Testing (PICT) is a confidential dialogue between a person attending a healthcare facility and a health care

practitioner aimed at enabling that person to make an informed personal decision about HIV testing in order to access treatment, care and support services. This process encompasses pre-test information and post-test counselling (NACP, 2007:3). Both the VCT and PICT approaches pick children after when they show up in the facility.

### **1.1.3 PMTCT coverage**

There are examples of effective Prevention of Mother to Child HIV Transmission (PMTCT) programme to prevent vertical transmission of the infection and in theory it should be possible to eliminate childhood HIV. High incidences of HIV have been associated with low coverage of PMTCT programme (Tammy et al, 2007: 474). In particular, many countries in Sub Saharan Africa have reported low coverage of PMTCT. As a result, over 40% of new HIV infections in the region are due to vertical transmission of HIV (Leyenaar, 2005:259). In contrast, higher coverage PMTCT programme have reported a significant reduction of maternal to child transmission of HIV to as low as 1% (Elijah & Warren, 2009:94). As described above PMTCT for HIV-positive pregnant women has remained low in many countries that have high prevalence of HIV. UNICEF reported poor coverage of PMTCT in Nigeria [3%] and Tanzania [15%], and moderate coverage in South Africa [50%] (UNICEF, 2008). In contrast, many of countries in the European and America regions with low prevalence of HIV have reported higher coverage of PMTCT programme for women who attend antenatal clinics. In 2010, Ukraine and Brazil both reported 90% coverage of PMTCT programmes (Low-Beer & Sarkar, 2010:12). A low coverage of PMTCT services has resulted in many children being born to HIV infected mothers who never tested for HIV and never received PMTCT prophylaxis. Kellerman & Essajee (2010) have reported that it is unlikely that these children will be identified unless there is a targeted testing strategy.

### **1.1.4 Care and treatment services for HIV positive children**

In recent years, progress has been made globally to expand access to antiretroviral therapy (ART) for both adults and children. Despite a dramatic increase in a number of HIV-positive children who received care and treatment services between 2005 and 2008, the number represent a small proportion of children who needed the services (Kellerman & Essajee, 2010).

Counselling and Testing for HIV is a critical initial step before ART is initiated. The 2010 United Nations (UN) report on HIV and AIDS epidemiology revealed that paediatric HIV counselling and testing services lag behind and are less developed as compared to HIV counselling and testing services for adults (UNAIDS, 2010:79-82). For example, in 2009, it was estimated that 1 276 000 children aged 15 years and below were eligible for ART; of this number only 356 400 (28%) were initiated on treatment (UNICEF, 2010:11-15). The question why there are so few children in ART has been asked for decades and Kellerman & Essajee (2010) in their report proposed a primary reason to be insufficient systems for identification and linkage of HIV infected children. A study done by Laufer, Van & Joep (2006:623) in Lesotho had similar findings indicating that children are largely underrepresented among those accessing treatment for HIV infection in Africa. Initiation of antiretroviral treatment to HIV positive children is a sole and powerful way of reversing escalating trends of child mortality due to HIV in many Sub Saharan African countries. Initiation of ART has a very significant impact on health outcomes. Data from the South African CHER study reported a 75% child mortality reduction immediately after initiation of antiretroviral treatments to children who were vertically infected with HIV (Violari et al, 2008:2233). A study conducted in Tanzania by Mmbando, Hartwig, Hofgren et al (2010:4) on social predictors of health outcomes among orphaned children described a number of major social determinants of health for infants and children with one or more parents dying or dead from HIV. These include pervasive poverty, weak community social support systems, lack of policy commitment by governments or foreign donors, lack of access to anti-retroviral drugs, limited access to schools, and gender limitations. Also a study conducted by Nöstlinger, Bartoli, & Gordillo (2006:29) reported that living with HIV positive children has been associated with challenges that interfere with provision of social support by guardians and some of the challenges include: lack of knowledge on how to care for children with HIV associated infections, poverty and stigma.

#### **1.1.5 HIV testing in children**

Evidence on missed opportunities to diagnose HIV infection in children and adolescents within the health systems have been reported (WHO, 2010:1). According to the World Health

Organization (WHO) report of 2009, only 8% of HIV-exposed infants received early virological testing in 2008 (WHO, 2009: 21-22). Analysis of international cohort data has confirmed that very few HIV-infected children are started on antiretroviral therapy; and those children who receive ART are started on treatment when they are already very sick, largely due to a delay in HIV testing (Sutcliffe et al., 2008:877). High prevalence of utilizing traditional healers in African countries has rendered effort to combat HIV/AIDS in the region. It is estimated that 80 percent of people in African countries consult with traditional healers before or during consulting with biomedical practitioners (Unite for Site, 2013) the practice that authors has been attributed to a delayed diagnosis of HIV in children (Allen, 2007:359). A study conducted in Zimbabwe to assess the effectiveness of PICT detection of children showed children are identified at a very late stage of HIV disease progression (Topp et al., 2012: 1735). Expanded access to HIV testing and counselling for children is reported by authors to have numerous benefits such as: (I) early identification of HIV-infected infants and children as a first step to treatment and care; (II) identification of HIV-exposed but uninfected infants, which facilitates follow-up care and prevention measures that help to ensure that they remain uninfected and healthy; (III) life-planning for parents and/or children who are HIV infected; and (IV) increased access to care and treatment services for children (WHO, 2007:14-17). Delayed tests for HIV have been reported to be associated with unwanted health outcomes such as poor adherence, increased frequency of opportunistic infections and death (Wortley et al., 1995:487). Cooke et al (2009:9) reported that timely access to care and treatment for HIV-infected infants and young children in South Africa remained an important challenge. Also a study conducted by Laufer, Van & Joep (2006:623) highlighted the need for examining different approaches to increase access to care and treatment services in children. Kellerman & Essajee (2010) also identified that HIV testing systems designed for adults do not meet the children's needs and it is a critical time for programmes to increase chances for children to access HIV testing services. The WHO report on a scale up of diagnosis of HIV in children underlined the fact that many HIV-positive children have no access to HIV diagnosis and treatment (WHO, 2008:11-19). Consequently, delayed diagnosis of HIV in children has caused huge barriers for the scale up of ART programmes and hence increased the burden of HIV among children.



### **1.1.6 Guidelines for HIV testing in children**

Guidelines for antiretroviral treatment have echoed the need for early initiation of treatment and have suggested significant virological, immunological, and clinical benefits (Carpenter et al, 1998:78). Many authors have named children with HIV disease “the missing face of AIDS” because they, more frequently than adults, lack basic health care and have been missing from global and national policy discussions” (UNICEF, 2005:3-5). The current national and international approaches for identification of HIV positive children include: Client initiated Voluntary Counselling and Testing [VCT] and Provider Initiated Counselling and Testing [PICT] (NACP, 2007:3 & WHO, 2010:7-12). A key statement in these guidelines is that “while HIV testing should be encouraged, it should be undertaken once the individual to be tested is both informed of the benefits and risks of testing and agrees to take it” (UNAIDS, 2004 & NACP, 2007:3). Two salient dilemmas do exist in the guidelines for HIV testing in children. Firstly, the guidelines require health care providers to obtain consent from legal guardians if they are to conduct HIV tests for children below 18 years (NACP, 2007:3 & WHO, 2010:8-12). The term legal in this context has remains unclear for providers and guardians and has posed huge barriers for utilization of HIV testing services for children. Reports have shown many children who are HIV positive are more likely to have lost one or both of their parents due to HIV and those who have lost both parents have tendency to shift between different care givers (Leyenaar, 2005:259) without necessary legalizing the process. Urassa, Boerma & Ngalula et al. (2001:2017) reported a 44% household mobility of family members in Tanzania after a death of the head of the household due to HIV and children are the most affected members of respective families. Secondly, the contents of the guidelines do not offer supportive procedures to be followed by health care providers for involving children when HIV testing services is offered to them (United Nations, 2003:2). Involvement of children through understanding their health is one of the salient determinants of good health outcomes. However, the need for child involvement varies based on their age and cognitive development and requires health care providers to be acquainted with these specific needs (WHO, 2011:9-13). The UN Declaration of Commitment on HIV/AIDS and the Convention on the Rights of the Child states that “HIV

testing and counselling is a fundamental to the rights and health of the children and should be made accessible along with the protection of their rights” (United Nations, 2003:2). Tanzania has endorsed the right in its National Guideline for HIV Counselling and Testing (NACP, 2007:2). Authors have brought attention to the benefits of exploring multiple sources of support, both personal (e.g. children’s friends, caregivers’ peers) and institutional (e.g. schools) for addressing many challenges that limit accessibility and the use-ability of medical services by HIV- positive children (WHO, 2011:9-15). In addition, WHO recommended a family-centred approach to HIV testing to ensure a maximal use of opportunities to identification of HIV-exposed and HIV-infected children (WHO, 2010:13).

#### **1.1.7 Disclosure to children**

A study conducted by Blasini et al. in Puerto Rico sought to assess disclosure model associated with healthy psychological adjustments and improved medication adherence among youth who are infected with HIV. In this review, the authors depicted 70% of youth had feelings of normality 6-months following HIV disclosure and their adherence had improved from both patients and caregivers. A study conducted by Bunn in Malawi supports the Puerto Rico findings. Bunn reports that “children knew more about their illness than they had been told, wanted to be told more and did better if they had had open and honest conversations about their illness” (Bunn, 2010:2)

Lori et al. (2007: 156) conducted a systematic review of literatures aimed to explore the patterns on disclosing HIV diagnosis to children and identify associated controversial and emotionally charged issues among health care communities, caregivers, and parents. Besides HIV disclosure, the paper also gave an overview of disclosure of cancer in children. The key findings in this review include: (I), reluctance to disclosure among caregivers and parents due to fear of emotional consequences such as disclose of secrets of family members, (II), when guardians and parents started to ask health care providers to not use the words HIV and AIDS health care providers became concerned about ethical issues,(III), a number of health care providers were reluctant to accept the idea of disclosing HIV to children at an early age, and

there are very few guidelines for health care providers and guardians to support HIV disclosure process. Most of the literature sourced for the review were from a single setting relying on the PMTCT linkages and had small sample size.

The analysis made by Lori et al had revealed a lack of evidence on the appropriate age for HIV disclosure in children, however; the authors gave a strong recommendation that HIV disclosure to children should be done at a school age.

#### **1.1.8 Response to HIV and AIDS in Tanzania**

A recommendation to increase coverage for PMTCT services from 12% to 80% was made by the government of Tanzania in order to bring maternal to child HIV transmissions to zero (HSHSP, 2007:8). However, the burden of HIV and AIDS in children has increased continuously (Victoria et al, 2007:327) despite the combined public and private sector coordinated efforts to combat the epidemic. In response to the increasing burden of HIV in children, the government of Tanzania strategized that by year 2012, 20% of people living with HIV who are initiated antiretroviral treatment (ART) to constitute children (HSHSP, 2007:8). Of people who were initiated ART in years 2008 and 2009 in Tanzania, only 7% and 8% were children (NACP, 2011:13). These findings are indicative of the urgent need for new ideas to enhance access and utilization of medical services for HIV-positive children in Tanzania. According to the Tanzania national guidelines for the clinical management of HIV and AIDS, initiation of ART in children age above 18 months require a confirmatory immunological test (NACP, 2005b:102), therefore accessibility of HIV testing services is crucial. In supporting the efforts made by the government of Tanzania to roll out ART services in children, Pastoral Activities and Services for People with HIV Dar es Salaam (PASADA) initiated a community based approach for identification of HIV positive children the Intensified Paediatric Case Finding (IPCF). The IPCF intervention had shown to increase the number of HIV-positive children who were enrolled in PASADA HIV clinics and those who were initiated on ART. These important findings suggested replication of the IPCF approach within Tanzania and other countries with high prevalence of HIV would improve access to ART for children eligible for the treatment; therefore evaluation of the IPCF is a critical initial step.

### **1.1.9 PASADA HIV care and treatment centre**

PASADA is a health and social service agency for people living with HIV and AIDS, operating under the umbrella of the Catholic Archdiocese of Dar es Salaam. The Organization started in 1992 as a community-based self-support group. PASADA added a dispensary to the existing services in 1994 and since then has experienced rapid professional growth in response to the increasing needs of people infected and by HIV and AIDS pandemic. PASADA is one of the first pioneer service providers in Tanzania that offers a comprehensive package of medical services free of charge to individuals regardless of their age, religious affiliations, sexual orientation, gender, and ethnic background thereby reaching all sectors of the community including the poorest. PASADA serves a target population of 3.5 million people and provides a wide range of services along the continuum of care including: (I) Voluntary Counselling and Testing (VCT) and ongoing supportive counselling, (II) HIV case management, (III) Provision of Anti-retroviral drugs (ARV), (IV) TB diagnosis and treatment, (V) Prevention of Mother To Child HIV Transmission [PMTCT], (VI) Home-based palliative care, (VII) Children's Palliative care, (VIII) Care and Support for Orphans and Vulnerable Children and (IX) Community Education (an HIV prevention programme). At the end of 2010, PASADA was providing comprehensive medical care to over 36 046 people living with HIV (PLHIV); of this number, 13 538 PLHIV were enrolled on ART and of these 1 218 (9%) were children (PASADA, 2010:15).

### **1.1.10. Intensified Paediatric Case Finding (IPCF)**

Intensified Paediatric Case Finding is an innovative approach of active identification of HIV-positive children. Contrary to other two traditional approaches for HIV testing, Voluntary Counselling and Testing (VCT) and Provider Initiated Counselling and Testing (PICT), the IPCF approach initiates the process of HIV testing for children by identifying children at a community level through utilization of community social networks whereas, VCT and PICT interventions initiate the process of HIV testing for children who have already presented at health facilities either for an HIV test or for other health issues. In addition, the IPCF approach widens the scope of people who may influence the initial process of an HIV test in children without violating the

legal obligation of primary caregivers to provide consent for an HIV test to their respective children.

Implementation of IPCF started in October 2009 with the goal of improving treatment outcomes for HIV-positive children, thus improving their quality of life. The IPCF approach is an appropriate intervention which aligns with the WHO recommendation presented early in the text (WHO, 2010) calling for family-centred approaches in order to maximize opportunities for identification of HIV positive children and bring them to appropriate medical care.

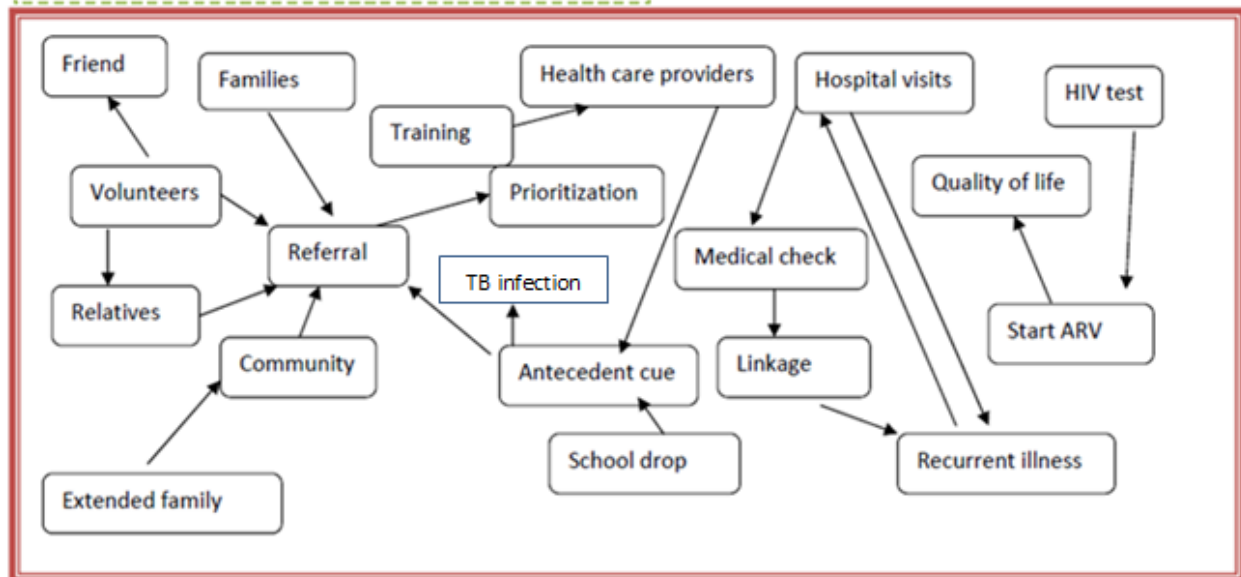
#### **A. Objectives of the IPCF intervention**

- I. To increase the percentage of HIV-positive children who were initiated on ART from 7% to 15% in Dar es Salaam by 2011.
- II. To increase the percentage of HIV-positive children identified with WHO clinical stage I or II of HIV disease by 40% in Dar es Salaam by 2011.

#### **B. IPCF milestones**

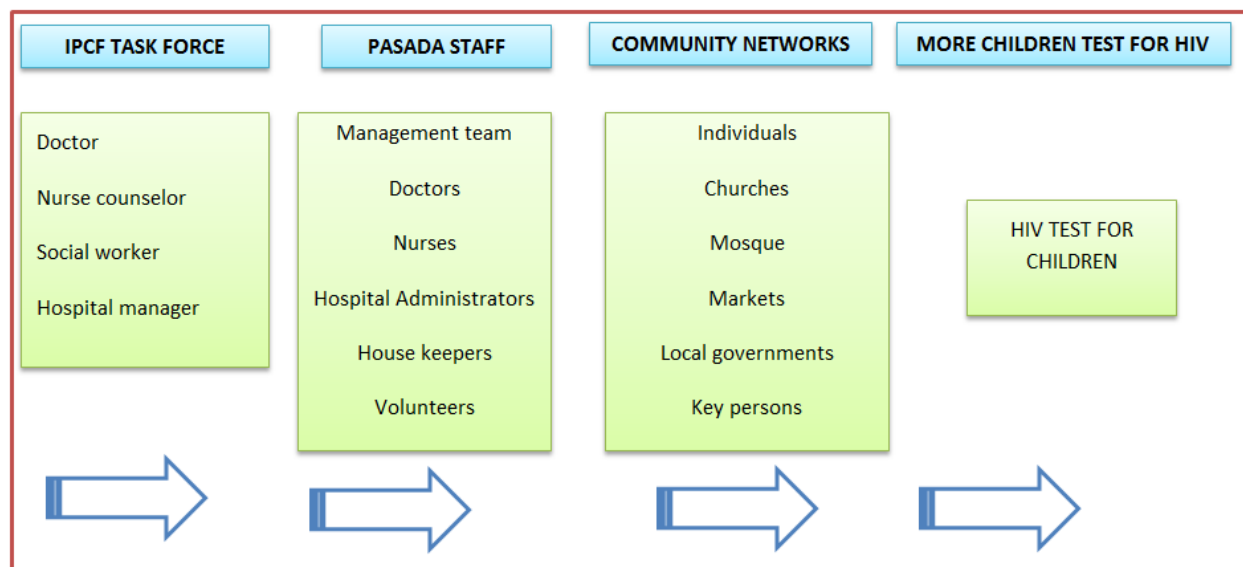
IPCF was developed through reflection exercises conducted amongst health care providers on the quality of the services offered by PASADA. These reflections were done mainly between professionals who were performing similar or closely related duties within the PASADA systems of providing care. In July 2008, the medical department of PASADA institute formed a paediatric task force which was asked to oversee and lead an initiative to identify innovative ways of reducing the burden of HIV amongst children. Compelling evidence of the increased burden of HIV among children was evident in many of the meetings held by the paediatric task force. School interruptions and drop-out, recurrence of opportunistic infections that necessitated multiple hospital admissions, poor adherence to ART, and deaths were some of the examples of poor health outcomes that were identified. Most of the reported cases of poor treatment outcomes came from observations based on daily clinical work, that many of children with poor health outcomes had received HIV tests at a late stage of HIV disease progression. As a result the paediatric task force developed an innovative way of reducing the described burden of HIV

in children through utilization of the unique nature of the African Extended Family (Figure 1: IPCF conceptual framework). The IPCF was officially launched in October 2009.



### C. IPCF implementation plan

**Figure 2: IPCF: Logic model**



IPCF TASK FORCE: designed the intervention and monitored the implementation

PASADA STAFF: Staff and selected volunteers received a train on IPCF and initiate the process by asking the key IPCF questions.

COMMUNITY NETWORKS: These are PASADA visitors, allies, and congregations that provided links between PASADA and HIV positive children in the community they lived.

MORE CHILDREN TEST FOR HIV: More children were expected to be identified, tested and linked to a care and treatment programme.

#### **D. Design and target population**

The IPCF intervention was primarily designed to benefit HIV-positive children who had yet to receive an HIV diagnosis. The intervention utilized the existing networks amongst and between health care providers, visitors, friends, families and patients of the PASADA institute. These groups of people were identified as “contacts” and were considered as allies whose key role was to link undiagnosed HIV-positive children with PASADA HIV testing centres. The intervention valued and utilized the existing unique nature of the African Extended Families. The extended family nature brought salient informational and clues that resonated with the overall goal of identification of HIV-positive children as early as possible and the children were linked to appropriate medical care. Three sets of questions were designed to instigate the

processes of identification of HIV-positive children. The questions were asked by health care providers and volunteers of PASADA and were directed to the IPCF networks within or outside service provision settings. Providers and volunteers were asked to assess the environment and willingness of the interviewee to hold a conversation that aimed at promoting health in children. Contrary to the PICT, the question aimed at identifying children who were still at the community and were likely to have no access to health services. The following set of questions were addressed to the contacts by PASADA staff: (1) whether they knew of children that they thought would benefit from an HIV test (2) if they were aware of children who had lost one or both of their parents and might have benefited from an HIV test. The contacts that had a “yes” response in either of the above questions were asked the third question; (3) whether they were willing to facilitate the process of linking children to PASADA clinics for appropriate medical check-up and subsequently care. IPCF coupons (Appendix VII) were designed to facilitate this referral process. Children who were identified through the IPCF approach had their clinical files designated with letter “C” on their initial evaluation forms. PASADA staff ensured that each step in the process of identification of children had retained confidentiality between healthcare providers and IPCF contacts. Also, procedures to disclosing HIV status for children and their guardians were done according to the Tanzania national guidelines for HIV counselling and testing. PASADA staff who worked at different sections played a major role at the beginning and the end of the implementation cycle of the IPCF strategy as described in the IPCF logic model in figure 2.

### **Rationale for the study**

This study is an evaluation of the IPCF strategy and aims to contribute toward better understanding of the root causes for persistently low number of children identified with HIV and subsequently initiated on ART. In this report, we describe the outcomes of IPCF intervention in a PASADA HIV programme and various social and clinical characteristics of HIV-positive children and their guardians.



## **1.2. Aim and objectives of the study**

### **1.2.1. Aim**

To examine the effectiveness of the IPCF approach in identifying HIV positive children eligible for ART and in initiating treatment compared to the traditional VCT approach

### **1.2.2. Objectives:**

- I. To determine the impact of IPCF on the number of HIV positive children identified before and after the intervention.
- II. To determine the perception of guardians on IPCF and VCT approaches of HIV identification.
- III. To assess the experience of living with HIV among children living with HIV and their guardians.
- IV. To compare characteristics of HIV positive children identified through IPCF and VCT approaches.

## **CHAPTER TWO: Methodology**

### **2.1. Study design:**

This is a prospective, cross-sectional descriptive study that used quantitative and qualitative methods for data collection and analysis. Data on the perception of children and guardians toward IPCF and VCT approaches, the experience of living with HIV among children living with HIV and guardians, and characteristics of children identified through IPCF and VCT were collected between January 2011 and April 2011. Data on the number of children enrolled in a PASADA programme seven months before and seven months after IPCF implementation were retrospectively gathered from a PASADA electronic database between June 2009 to December 2009 (before IPCF intervention), and January to July 2010 (after IPCF intervention) and the two groups were compared.

### **2.2. Study site:**

IPCF study took place in Temeke, Ilala, Kinondoni and Mkuranga districts of the municipality of Dar es Salaam and Coast regions, in Tanzania within PASADA clinics that include: Upendano, Tegeta, Mbweni, Kawe, Msimbazi, Yombo, Ukonga Vikindu, Mkuranga and Mbagala.

### **2.3. Study population:**

HIV-positive children aged between 8 and 18 years, parents, and guardians of HIV-positive children who received medical care at PASADA clinics between January and April 2011. Also children who attended PASADA clinics and were registered in the PASADA data base between June 2009 and July 2010

### **2.4. Inclusion criteria:**

For objective one: children below 18 years enrolled in a PASADA clinic between June 2009 and July 2010; for objective two and three: HIV positive children and their guardians attending PASADA clinics between January and April 2011; for objective four: children aged 8 to 18 years attending PASADA clinics.

## 2.5. Exclusion criteria

For objective two, three & four: HIV positive children below 8 and above 18 years and children tested negative for HIV. Children who are above 18 years are considered adults and those below 8 years were considered young to be involved in focus group discussions and interviews.

For objective one all children below 18 years who tested HIV negative.

## 2.6. Sample size

For objectives one and four a sample size of 204 participants was derived with alpha level 5% and 90% power using a STATA command sampsi.

```
[sampsi 32 36, alpha(.05) power(.9) sd(5.6) sd(12) ratio(2)].  
Test Ho: m1 = m2, where m1 represents a monthly mean number of HIV-positive children  
identified before-IPCF intervention and m2 stands for a monthly mean number of HIV-positive  
children identified after-IPCF implementation at PASADA clinics.  
Assumptions: Alpha level= 0.0500 (two-sided)  
Power = 0.9000  
m1 = 32, m2 = 36  
sd1 = 5.6, sd2 = 12  
n2/n1 = 2.00  
Estimated required sample sizes:  
n1 = 68  
n2 = 136
```

In response to objectives two and three, a total of 30 focus group discussions each group with 7 participants on average. We chose this average number of group participants for convenience and to ensure representation of people from both IPCF and VCT groups.

## 2.7. Research team

A team of six research assistants were recruited among PASADA staff. The team received three day training on use of the research protocol and ethics of conducting research in children. PASADA has over fifteen years of experience of working with HIV-positive children through provision of medical care, psychosocial, emotional, spiritual and legal support. In this regard, recruited research assistants had experience and skills in dealing with children. The training emphasised the fact that children should be recognized as vulnerable population thus ethical considerations were observed accordingly.

## **2.8. Data collection**

Implementation of the IPCF intervention started in January 2010 and continued through 2011/12. Data on the impact of the intervention was collected seven months pre-intervention (June-December 2009) and seven months post-intervention (January-June 2010).

### **2.8.1. Data collection tools**

Questionnaires and focus group discussion (FGD) guide were the main tools for data collection in response to objective 2, 3, and 4. These tools were developed initially by staff working in a paediatric division of the PASADA's medical department through review of literature, clinical experience of researchers and consultations with the research supervisor. The tools were tested at three PASADA clinics other than those involved in the study and were modified according to the minor discrepancies denoted and re-tested to one of the PASADA clinics. In response to objective 1, record on patients' attendance at PASADA clinics were obtained from electronic data-base.

### **2.8.2. Data collection methods**

Both focus group discussions and interviews were conducted in Swahili language which was fluently spoken by research assistants, guardians, parents and children who participated in the study. The questionnaire captured information on demographics, detail about the child's illness, and information was verified by chart review of the clinical records. A FGD guide (Appendix III) was used for adults and children discussions to collect information on participants' experience of living with HIV and their perceptions on the approaches for HIV identification.

### **2.8.3. Data collection process**

#### **❖ Survey data for objective one and four.**

Recruitment: informants were randomly selected from registration log books at the reception of PASADA clinics where all patients had listed their names prior to accessing medical services.

PASADA had children's clinics run separately from that of adults. In each of the children's clinics a research assistant was stationed at the reception and recruited participants. Every third child who came to the clinic were approached and requested for their consent and assent to participate in the study and those who accepted were included in the study. Research participants were gathered and explained the purposes of the research and that their participation would not result into financial benefits or any form of privileges. Research participants were given an opportunity to ask questions that clarified the research process. Participants were informed that they were allowed to withdraw from the study at any point time without being penalized. Each of the children and their parents or guardians who participated in the research had their respective verbal assent and written consent obtained and each of the interviews was conducted for an average of 30 minutes.

Information relating to response to objective four of the study was obtained through researcher administered questionnaires. Each of administered questionnaires was verified by the principle investigator within two days after being completed. All questionnaires were administered during the first four months of the study (January to April 2011), and individual chart reviews were done between August and December 2011.

❖ **Qualitative data: focus group discussion: Objective two and three.**

Recruitment of participants: informants for focus group discussions were recruited through purposive sampling from a pool of clients who attended PASADA HIV clinics. Both adults and children who participated in the research were approached and asked if they agreed to participate in the study. Participants were informed that their involvement were not going to result into financial gain or any other form of benefits and rather the information gathered from the research is intended to improve delivery of health services in children living with HIV. In addition, participants were given opportunity to ask questions on the research and clarifications were given. Participants were also allowed to withdraw from the research without being penalized as a result of their decision. Written consents were obtained from guardians or parents following verbal assent of their respective children. Participants gave the permission to

record the conversations during focus group discussions. Participants were informed that confidentiality during discussions could not be guaranteed especially during group discussions although; research staff was committed to maintain confidentiality by signing a confidentiality agreement form whereas research participants were not required to provide the same commitment. It took an hour on average to conduct one focus group discussion. Participants were given money to compensate the cost for transportation and the time spent for the research.

Focus Group Discussion procedures: children had their focus group discussions conducted separately from that of adults. Children of age groups 8 to 13, and 14 to 18 years had their group discussions conducted separately according to the research protocol. Decision to separate the two groups of children based on their age was made to favour those with closely related milestones to be in same group discussion to allow robust interactions among participants. Each of the group discussion had two research assistants: one as a facilitator, and another as a note taker. The focus group discussions comprised of 6 to 8 participants and at least three participants were identified through each of IPCF and VCT approaches.

The topics that guided the discussions were on HIV social implications, perceptions on HIV services, and HIV health related outcomes. The conversations in the focus group discussions were tape recorded by the analogy Sony Cassette Recorder devices. Field notes were also taken where non-verbal actions and emotions were as well captured. A total of 10 focus group discussions were conducted among children aged 8 to 13 and 8 focus group discussions among children aged 14 to 18 years, while 12 focus group discussions were conducted among guardians. During focus group discussion conversations, research assistants ensured that comparisons were made between participants in the IPCF and VCT groups to ensure that each of the topics was covered throughout all 30 focus group discussions we conducted.

Subsequent group discussions were conducted until a point of data saturation was reached. Transcription was done verbatim by one of the six research assistants who were not involved in

actual group discussions. Each of the transcripts was then reviewed by at least one of the five research assistants. In addition, the principle investigator randomly listened to the recorded conversations and did a comparison with the transcripts for accuracy.

All transcripts were translated by the principle investigator from Swahili to English before analysis was done and translations were verified by an independent reviewer.

## **2.9. Data Analysis**

### **❖ Survey data**

We developed a Microsoft Excel spreadsheet with variables which were present in the questionnaire. All variables for 227 respondents were imported to a spreadsheet and data were saved as an Excel Workbook. Different codes were then generated for identification of participants and the column with client's registration number was dropped to maintain confidentiality. A new Excel workbook was generated and used by the researchers throughout data analysis. The excel sheet was then uploaded in STATA software Inc. 12 for analysis. We made comparisons of two groups IPCF and VCT on social and health characteristics in response to object four for variables such as: sex, number of parents currently alive, education level of the child, adult accompanied the child to a clinic, time spent travelling to a clinic, primary care giver status, CD4 count at first clinic visit, number of health care providers visited by prior an HIV diagnosis, time interval from diagnosis of HIV and disclosure, linkage to specialized services, WHO clinical stage at first visit, ARV status, opportunistic infections preceded an HIV diagnosis and status of the accompanied guardian. We ran a Pearson Two Sided T-Test to make a comparison on the children's characteristics between IPCF and VCT groups. We used the Pearson T-test (parametric test) based on the assumption that the sample size we used to compare characteristics of children of adequate size and had followed a normal distribution. Each of the children participated in the study had a chance to be identified by either of the two approaches IPCF or VCT therefore analysis of the data was done according to the methods of identifying their HIV positive status.

In response to the study objective one, we assessed the effect of IPCF intervention on the number of children who were tested HIV positive and enrolled in HIV clinics seven months before and seven month after the IPCF intervention. This information was obtained from the PASADA electronic data base.

In additional we assessed the effect of IPCF intervention on the number of HIV-positive children who were initiated anti-retroviral drugs seven months before and after the IPCF intervention. We ran a Kruskal-WallisTest to assess the statistical differences in the two time periods. We chose this non parametric test because participants in the two periods had a chance to be counted twice and comparison was made on ranks (months) of seven months. We therefore could not make an assumption on the distribution of population before and after intervention.

In answering study objective four we used odds ratio (IPCF/VCT) in order to compare the characteristics of children in the IPCF and VCT groups.

#### ❖ **Qualitative data**

##### Familiarization:

Researchers participated in the focus group discussions which facilitated an initial understanding of the researched subject. Following verbatim transcription and translation of the conversations, transcripts were read repeatedly by the team to enhance familiarization of its contents.

In the whole process of transcription and rereading of the transcripts, researchers avoided to comment or categorize the information in order to reduce the chances of their personal influence on data analysis. The research team were very familiar with the types and location of particular information in the text the fact that enhanced development of themes and sub-themes.

##### Issues:

While familiarization with the data continued, researchers started to identify phrases with complete messages and each of the phrases was highlighted with different colours. The phrases



were assigned codes indicating which parts of the interview they had been taken from. Phrases were then cut and those with close related messages were grouped and posted on the wall under one heading describing the contents and resulted into topics. While generating themes researchers did not find easy to organize phrases which had cross-cutting messages. Also, grouping of emotional expressions from participants was not easy.

#### Themes:

Different messages in each of the groups were studied and rearranged to formulate a logical flow and linkage of ideas. A total of three themes were eventually generated through rearrangement of thoughts and messages which were captured during focus group discussions.

#### Sub-themes:

Content analysis of the themes was done by researchers and information with closely related messages was merged under each of the themes to formulate sub-themes. We constantly reviewed the contents of sub-themes and comparisons were made between chosen sub-themes to ensure sub-themes with significant information were retained. Organization of sub-themes was done to ensure a logical flow of ideas is maintained. A total of thirteen sub-themes were generated.

#### Reflexivity:

Researchers are part of service delivery of the paediatric division in a study site; therefore, personal judgements that could influence data analysis were addressed by reminding researchers to remain neutral and non-judgemental in every step of the research.

#### Internal validity:

The choice of research tools; focus group discussion and structured questionnaire was made to ensure internal validity of the research. The use of focus group discussion enabled researchers to better understand the group dynamics and gather rich information which on the other had helped researchers to understand the topic and enhanced administration of questionnaires.

### **2.10. Data storage privacy and confidentiality**

Unique identification (ID) numbers were allocated to all research participants and all identifiers were kept separate from the data which were used for analysis. Questionnaires, cassettes and

field notes were also labelled and stored in a locked cabinet and access to research material was restricted to the research team members only. Electronic data were stored in an external hard drive and access to the information was password-protected and strictly limited to the research team. The research materials will be destroyed in a five year period following dissemination of the research findings.

#### **2.11. Ethical considerations**

Children and guardians participated in the research were fully informed on the purpose of the research and that there were no financial or other form of gain as a result of participating to the study. They were also provided with ample time to ask questions pertaining to the study, and clarifications were provided. Participants were assured that any of their decision to participate in the study or withdraw from the study at any point was not going to affect the care they are entitled to get from PASADA. Participants were allowed to withdraw from the study if at all they chose to do so. Children who were enrolled in the study and identified with health problems were provided with assisted support that linked them to appropriate channels of care. If children exhibited psychological stress during interview process, researcher assistants would terminate the process and refer the child to appropriate channels of care.

Permission to conduct this research was obtained through the Tanzania National Institute for Medical Research. Ethical approval from the University of Cape Town FHS HREC #363/2010

## CHAPTER THREE: Results

The results are presented in two parts: quantitative data relevant to objectives 1 and 4 and qualitative data relevant to objectives 2 and 3. The quantitative data is presented in table 1, 2, and 3 and qualitative data in table 4. Table 1 presents social and demographic data, whereas and table 2 presents information on health characteristics of children participated in the study. Data on the impact of the IPCF approach on the PASADA programme is presented in table 3 and that on the experience of living with HIV among research participants is presented in table 4.

### 6.1. Quantitative results

#### 6.1.1. Social and demographic characteristics.

A total of 227 participants were enrolled in the study (VCT=76 and IPCF=151), which is beyond the required sample (204). The average ages of children participants in the IPCF and VCT groups were 11.3 and 12.3 years respectively (P-Value 0.007). There was no difference in proportions participants based on their sex. The proportions of males in the IPCF and VCT were 51% and 50% respectively, and that of females were 49% and 50% for the IPCF and VCT groups respectively (P-Value=0.89). IPCF group constituted 12%, 77%, and 11% of children with none, primary, and secondary levels of education respectively, while, those in the VCT constituted 16%, 43% and 41% of children with none, primary, and secondary levels of education respectively (P-Value 0.049). In the IPCF and VCT groups 82% and 88% respectively, spent less than 3 hours travelling time to the clinic whereas 18% and 12% in the IPCF and VCT, respectively, spent over 3 hour time travelling to the clinic (P-Value=0.26). A majority of children in the IPCF were cared by biological parents compared to children in the VCT group. Of those who were interviewed, 45%, 21%, 25% and 9% in the IPCF group and 37% 29%, 26% and 8% in the VCT were cared by biological parents, aunt/uncle, grandparents, and non-relatives respectively (P-Value=0.48) Table 1.

**Table 1: Demographic characteristics of study participants**

Variable	IPCF (n=151)		VCT (n=76)		Odds Ratio	P-value
	Number (n) or mean	(%) or SD	Number (n) or mean	(%) or SD	IPCF/CVT	
Sex						
Male*	77	51%	38	50%	0.96	0.89
Female	74	49%	38	50%		
Age	11.3	3.5	12.6	3.4	0.89	0.007
Number of parents currently alive						
Two*	35	23%	12	16%	0.7 0.6	0.39
One	63	42%	33	43%		
None	51	34%	31	41%		
Education of child						
None*	18	12%	7	9%	0.9 0.4	0.049
Primary school	116	77%	51	67%		
Secondary school	17	11%	18	24%		
Time spent travelling to clinic						
0 to 3 hours*	120	82%	66	88%	1.6	0.26
> 3 hours	26	18%	9	12%		
Primary caregiver						
Biological parent*	68	45%	28	37%	0.58 0.78 0.96	0.48
Aunt/Uncle	31	21%	22	29%		
Grandparent	38	25%	20	26%		
Non-relative	4	9%	6	8%		
Accompanying adult at a clinic						
Biological parent*	64	42%	28	37%	0.74 0.8 0.9	0.84
Aunt/Uncle	39	26%	23	30%		
Grandparent	33	22%	18	24%		
Non-relative	15	10%	7	9%		

\* Reference group

#### 6.1.2. Health characteristics:

Children in the IPCF and VCT who had CD4 count above 500 cells/ml were 42% and 34% and those with CD4 count less than 200 cells/ml were 33% and 33% respectively (P-Value=0.611).

The research depicts a significant difference in the number of hospital visits made by children in the IPCF and VCT groups. Children in the IPCF group had multiple hospital visits suggesting that they were likely to be missed by the VCT approach. We found 46% and 31% of children in the

IPCF and VCT visited over 3 healthcare providers prior to an HIV diagnosis (P-Value 0.001). Lack of disclosure of HIV status to children was prevalent in the two groups, however; more children in the IPCF (46%) compared to 29% in the VCT had undisclosed HIV status (P-Value=0.005). There was no difference between the two groups on the number of children who were initiated on anti-retro viral treatment. The commonest opportunistic infection reported among children in both groups were upper respiratory tract infections 39% (for both IPCF and VCT groups and skin infections 34% for the IPCF and 38% for the VCT groups (P-Value= 0.478). Other health characteristics are presented in table 2.

**Table 2: Health characteristics of study participants**

Variable	IPCF (n=151)		VCT (n=76)		Odds ratio	p-value
	Number (n) or mean	(%) or SD	Number (n) or mean	(%) or SD	IPCF/VCT	
CD4 count at first visit (c/ml)						
> 500*	63	42%	26	34%		0.611
350-500	15	10%	10	13%	0.8	
200-350	23	15%	15	20%	0.7	
< 200	50	33%	25	33%	0.6	
Number of healthcare providers visited prior to HIV diagnosis						
None*	27	18%	34	45%		0.001
1-2	54	36%	18	24%	3.5	
3+	70	46%	24	31%	4.5	
Time interval from diagnosis of HIV-status to disclosure (months)						
0 to 3*	20	13%	24	32%		0.005
4 to 6	18	12%	6	8%	3.6	
> 6	43	29%	23	31%	2.2	
Not done	68	46%	22	29%	3.7	
WHO Clinical stage						
Stage I*	19	13%	16	21%		0.332
Stage II	91	60%	41	55%	1.9	
Stage III	33	22%	13	17%	2.1	
Stage IV	8	5%	5	7%	1.3	
ARV Status						
Currently taking ARV*	90	60%	45	59%		0.955
Not currently taking ARV	61	40%	31	41%	0.98	
Initial diagnosis						
Malnutrition	4	1%	1	4%	0.4	0.478
Tuberculosis	7	5%	4	5%	0.6	
Skin	51	34%	28	38%	1.1	
Respiratory	59	39%	29	39%	1.1	
GIT	20	13%	4	5%	1.3	
Other	13	9%	10	13%	3.1	

\* Reference group

A multiple logistic regression was run to assess the odds of health providers visits made by children in the IPCF group compared to those in the VCT. After adjusting for age and sex, the

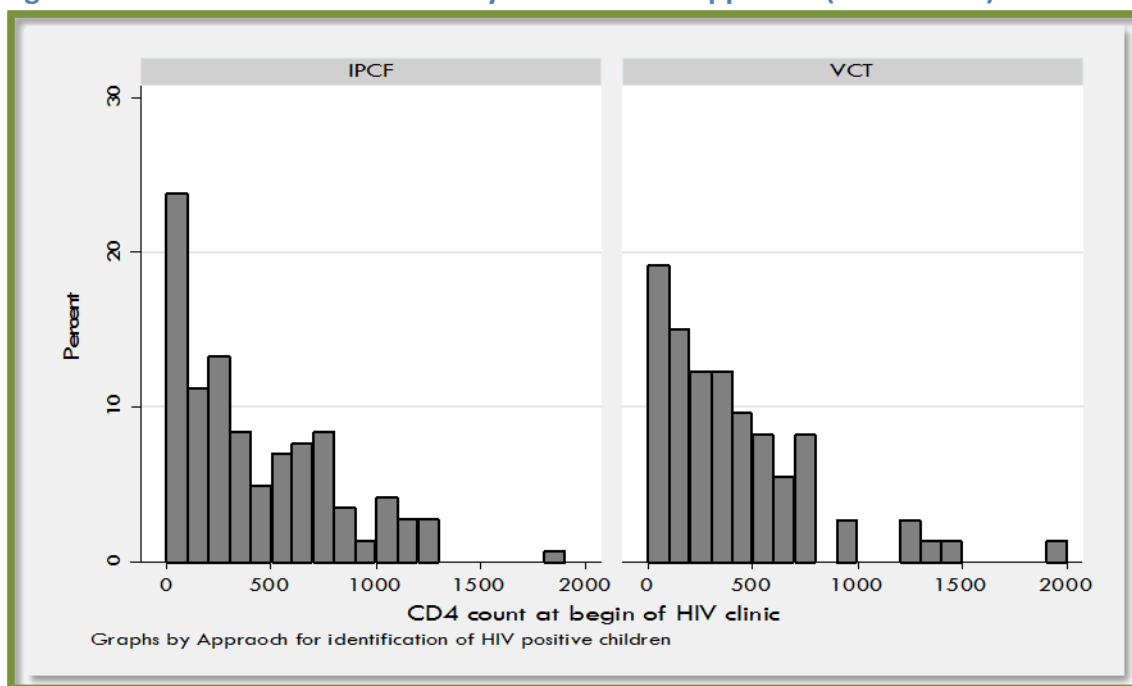
children in the IPCF group had over 5 times odds of visiting more than three health care providers compared to those who were in the VCT group (P-Value < 0.001) Table 3.

**Table 3 IPCF/VCT Logistic regression results, selected characteristics IPCF study, 2012**

Variable	Un adjusted odds ratio		SE	Adjusted odds ratio	
	OR	P-Value		OR	P-Value*
Intercept	9.0		10.13		
Age	0.89	0.008	0.046	0.87	0.007
Gender					
Male	1				
Female	0.96	0.8877	0.376	1.2	0.651
Number of facilities visited prior to start HIV clinic					
None	1				
One	3.5	0.004	2.619	5.4	0.001
Two	4	0.005	3.353	6	0.001
≥Three	4	<0.0001	2.103	5.2	<0.0001

\*P(Value adjusted for Age, Sex, Number of facilities visited,  
OR (Odds ratio)  
SE (Standard Error)

**Figure 3: Distribution of CD4 count by identification approach (IPCF vs VCT)**



IPCF group has children with both higher >500 and lower <500 CD4 count and majority of children in the VCT group have low CD4 count (P-Value >0.5)

### 6.1.3 Impact of the IPCF on the PASADA programme.

On average 28 children and 48 children respectively tested HIV-positive per month for the period of seven months before and after the IPCF intervention (P-value 0.001). Also on average 19 and 27 children were respectively initiated anti-retro viral treatments seven months before and after the IPCF intervention was implemented (P-Value 0.02) Table 4.

**Table 4: Children tested HIV-positive and enrolled in a PASADA care and treatment center**

Children tested HIV-positive and started on anti-retroviral treatment				
Year-2009 (Before IPCF)			Year 2010 (After IPCF)	
Month	Children Tested HIV-Positive $\bar{x}=28$ , $SD=4.7$		Month	Children Tested HIV-Positive $\bar{x}=48$ , $SD=7.8$
June	24		January	41
July	33		February	49
August	23		March	47
September	32		April	43
October	28		May	64
November	32		June	48
December	22		July	42
$\bar{x}$ -Mean , $SD$ - Standard deviation				

A sustained increment of number of HIV positive children who were enrolled in a PASADA program seven month after start of the IPCF intervention compared to seven months before implementation of the intervention.

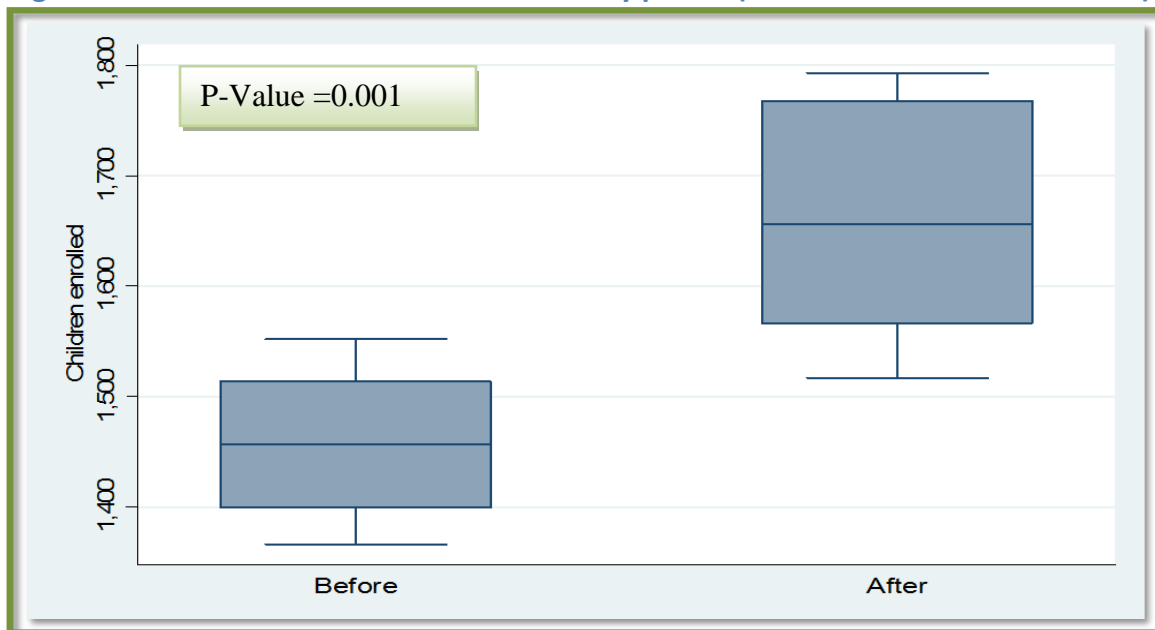


**Table 5: Children tested HIV-positive and started on ART at PASADA clinics**

Children tested HIV-positive and started on anti-retroviral treatment				
Year-2009 (Before IPCF)			Year 2010 (After IPCF)	
Month	Children Initiated ART $\bar{x}=19$ , $SD=2.6$		Month	Children Initiated ART $\bar{x}=27$ , $SD=5.7$
June	18		January	17
July	22		February	23
August	19		March	34
September	20		April	27
October	21		May	32
November	14		June	27
December	18		July	29
$\bar{x}$ -Mean , $SD$ - Standard deviation				

Table 5 shows increased number of children tested HIV positive that are initiated on ARV. However, a low proportional of children who are initiated on ARV is seen in the seven months after implementation of the IPCF intervention. The low proportion could be explained by the short study period; also initiation of ARV requires a thorough assessment of social and clinical wellness of both the children and their guardians and it is a time consuming. Also despite a huge number of HIV positive children identified by the IPCF intervention, these children may also not qualify for ARV due to low CD4 count or other health reasons.

**Figure 4: Children enrolment PASADA clinics by period (7 months Before vs After IPCF)**



More children were tested HIV positive and subsequently enrolled in a PASADA care and treatment programme.

## 6.2. Qualitative findings

A total of 30 focus group discussions were conducted: 10 for children aged 8-13, 8 for children aged 14-18 years and 10 for guardians and parents. Table 6 summarizes characteristics of participants of involved in the FGD.

**Table 6 Characteristics of participants in focus group discussions, IPCF study 2012 .**

Focus group	Number of FGD	No. of participants	Average age (Years)	Gender		Mode of diagnosis	
				Male	Female	IPCF	VCT
8-13	10	122	12.5	42	84	87	35
14-18	8	62	16	30	32	20	42
Guardians	12	129	48	57	72	74	55

Three themes and thirteen sub-themes were generated as summarized in table 6.

**Table 7: Themes analysis IPCF study**

THEME ONE	THEME TWO	THEME THREE
<b>HIV Social implications</b>	<b>HIV services</b>	<b>Health outcomes</b>
I. Parental loss	I. Poor adherence	I. Improved health status
II. Attachment of children	II. Children concern about lack of disclosure	II. Recurrent illnesses
III. Stigma and discrimination	III. Approach to HIV identification	
IV. Witch craft	IV. Disclosure at a household	
V. Children social responsibilities	V. Legal services	

### THEME ONE: HIV social implications

#### I. Parental loss

Many children appeared to have experienced a loss of one or both of their biological parents. This observation persisted in both groups of children aged 8 to 13 and 14 to 18 years. However, fewer children in the older group (14 to 18) reported to have living parents. A 14 year old female child, identified through IPCF said,

*“I am very sad [low tone], my mother died when I was in standard six, she left me with my two siblings. My dad also died two years later and I moved and stayed with my aunt. Shangazi [Aunt] could not stay with me as she said, I was too ill and therefore she sent me along with her friend to her sister who is my other aunt as well... Shangazi mdogo [Aunt’s sister] took me to my grandmother for a short period I stayed with her. I was still sick and thank you for [name of volunteer] who advised my grandmother to bring me to PASADA. Now I don’t get sick as I used to, and I am now going to school”.*

Participant 4: FGD 10

The research revealed that guardians who were biological parents were more likely to have children of a much younger age compared to guardians who were not biological parents. A 16 year boy identified through VCT said,

*“My father passed away before I started primary school and together with my mother and my siblings we went to stay with my uncle. The life thereafter became so difficult we moved to [name of town he live] and we established small business for income generation. Then my mother died...Now I am able to go back to school after joining PASADA programme”.*

Participant 1: FGD 12

## **II. Attachment of HIV positive children**

Majority of children had moved over three times between different caregivers. A 13 years boy identified through VCT said,

*Before I stayed with my grandmother, I lived with uncle [name], my sister and my aunt who live in [name of a place] and I was very sick. My sister and my aunt brought me back to Dar where I stayed with my grandmother...”*

Participant 3: FGD 1

The same phenomenon of shifting between different family members was reflected in both children and adults focus group discussions. One grandparent guardian said,

*Mjukuu wangu [my grandchild] before he came and stayed with me had stayed with his uncle, his sister and his two cousins. I could hardly tell what was wrong with him until when I was advised to come to PASADA and tested him...."*

Participant 4: FGD 21

While shifting between caregivers, most children stayed with their paternal uncle or aunt as a primary care giver following a parental loss. Other members of the family often came later in the series. A sixteen year old girl said,

*"After the loss of both of my parents, I stayed with my uncle and my aunt. My aunt brought me to PASADA and she told me to come to PASADA whenever I get sick..."*

Participant 3: FGD 16

The trend of shifting for many children ceased when children were cared by grandparents. A small proportion of children had lived with people who are not biologically related to the child. One family friend guardian said,

*"...Mwanangu [name of the child] is very close to my children and after a loss of both their parents who were very good friends of my family; we decided to stay with [name of the child] and now she goes to school just like her fellows"*

Participant 6: FDG 22

### **III. Stigma and discrimination**

Stigma and discrimination were featured in both adults' and children's group discussions. Guardians, in particular, reported stigma being one of major challenges of living with a HIV-positive child and it is prevalent at a family, community and work places. A number of guardians had associated stigma with financial constraints they encountered. *Guardian of 8 year old boy whose child were identified by VCT approach said,*

*"I used to work as a secretary for a business company and when my son was diagnosed with HIV, I had to quit the job that I had in order to take good care of my son as needed. I did not want anybody to know the status of my son in*

*order to protect him from being discriminated by other people. It is very hard [pause] em... For instance I have no reliable income to sustain my life and keep up with living expenses; I have nobody to support me and my relatives..."*

Participant 2: FGD 19

Episodes of stigma and discrimination were also prevalent amongst children of age 14 years and above. *Thirteen year old boy identified by VCT said,*

*"I was very disappointed by other pupils who made fun of me, they were picking on me. They were, calling me names such as 'mama VVU' [Swahili word means mother of HIV] and some did not let me play with them."*

Participant 3: FGD 2

At a house hold level, children had reported to experience being stigmatized by their caregiver. A 16 year old child reported to be socially discomfort with the way how his aunt took care of him when compared to other siblings. *A 14 year old boy identified through the VCT approach said,*

*"My aunt used to wear plastic bags on her hands when she was washing my cloths.... I could see her through the window as she did not do openly. She separate my cloths with that of other children, I was very sad and asked why... and I did not get an answer clothes until when [name of doctor] had decided to conduct a meeting with my family and therefore my aunt stopped the behaviour"*

Participant 5: FGD 3

#### **IV. Witchcraft and HIV**

Existence of belief that associated HIV with witchcraft was featured in group discussions of both adults and children. None of the guardians admitted directly to be involved in the practice, although, participants admitted that the practice existed. A guardian of a 16 year old girl said,

*“My child started to experience recurrent illness when she was in her first year of secondary education and her aunt suggested that she was bewitched, however; I did not believe to be the case... and I brought her to PASADA and now she is progressing well”*

Participant 2: FGD 11

Similarly, children mentioned that they knew people who associated HIV with witchcraft. One child said,

*“I was very sick... and my grandmother used to tell me I was witched and that being a major reason for my illness. My sister took me to PASADA and that was the end of my illness, now I have no more fever and pain”*

Participant 3: FGD 6

#### **V. Children social responsibilities**

We found, majority of children who were full orphaned assumed more social responsibilities such as keeping of medical records, preparing food for the family, and taking care of other siblings. A 16 year old boy said,

*“I stay with my grandmother and my three siblings in [name of a place] and I prepare food for the family, fetch water before I go to the school and go to the clinic...”*

Participant 3: FGD 18

### **THEME TWO: HIV Services**

#### **I. Poor adherence to antiretroviral drugs (ARV)**

Poor adherence to ARV in children was evident in the children’s discussions. Children expressed the feelings of hating taking the ARV especially when there was not adequate information that describe the reasons for taking the drugs.

*My mother used to tell me to take the drugs, but I did not like them. I used to get sick and the doctor told me it is because I have not been taking the drugs properly. Now I take the drugs and my health is good..."*

Participant 2: FGD 8

## **II. Children concern about lack of disclosure**

A concern of the lack of openness in guardians on the topic of disclosure was reported by most of the older children (14 to 18 years). A 17 year old boy said,

*I used to ask my aunt what was wrong with me... I decided to test for HIV during presidential campaign and I was told that I am infected with HIV..."*

Participant 6: FGD 18

Also, guardians were reported by children to be reluctant in disclosing HIV to children.

*"I asked mama mdogo [step mother] why was I taking medicines every day, and neither of my siblings were taking them, mama mdogo-told me that I had chest problem so I had to take them. I asked her why was I taking them continuously even at times that I was not ill,...she told me the drugs were for preventing the illnesses I was born with, and insisted I have to take them ..Eh, but I hate them. My doctor was also telling me to take them".*

Participant 1: FGD 18

A number of older children knew their HIV status at a younger age and they were conversant to talk about issues related to their health.

*"I heard a doctor speaking about HIV every day when I came in the clinic...and I asked a doctor in the pharmacy [ARV dispensing nurse] and she explained to me that I was infected with HIV..."*

Participant 5: FGD 17

### III. Identification of HIV positive children

HIV tests amongst children were often preceded by symptoms of recurrent illnesses. Majority of children had experienced episodes of recurrent illnesses before an HIV test.

*"I used to get chest pain, diarrhoea very often until when my aunt decided to bring me to PASADA and I was tested for HIV. Now I am I am doing fine..."*

Participant 4: FGD 13

An expression that an HIV diagnosis was delayed featured in adults' group discussions. Several guardians reported to have made repeated hospital visits and others lost their children, nonetheless; an HIV test was still not conducted. One of the guardians reported to have been frustrated by the systems of testing children which she claimed to have resulted to loss of her two children. During conversations, guardians and parents whose children were identified through IPCF appraised the system and considered as a saviour to their children. One biological parent said,

*"I lost two of my children who were ill for a while. My first born was four years old and my second born was three. They both had [paused and wiped tears] ...every time when I went to a doctor, the doctor told me that my children had malaria and pneumonia, I wish the doctor had tested them for HIV [paused with deep sorrow. I think they would have not passed away, thank you [name of staff] and thank to PASADA....my son couldn't be healthy without ..."*

Participant 2: FGD 23

Missed opportunity for an HIV test among children was also revealed in the adults' group discussions. Many guardians had a notion those older children who had no history of recurrent illnesses, had a negative HIV status in spite of the HIV positive status of the parents. One biological parent said,

*"I have so much to thank to PASADA for initiating a test to my child as I had never thought kijana wangu [older son] would possibly be infected with HIV as well... as he had no any problem problems... yaani [thrilled with the situation] oh! Oh! Thank you for opening my mind and rescuing my family"*

Participant 2: FGD 24



#### IV. HIV disclosure at a household level.

Biological parents who participated in the discussions had a similar pattern of HIV disclosure between partners and their children. A biological parent of a child identified through the IPCF said,

*"I am a mother of three children; I received an HIV test for the first time three years ago and after a year I decided to share with my late husband who was also tested. We both joined a PASADA clinic... and this year through a support of [staff name] all three children were tested..."*

Participant 3: FGD 20

Most of the times it followed that; one parent, would know his [her] HIV status followed by the second parent and the child would come last. A 16 year old girl said,

*"Before the death of my mother due to HIV, my mother spoke to my sisters and told them that they should take a good care of me as I will be the neediest one in the family... I was immediately tested for HIV after my mother's death, and now I am healthy and progressing in school"*

Participant 6: FGD 15

#### V. Legal services

Many barriers to accessing legal services existed among guardians of HIV-positive children. A number of children expressed their concern on the ways families handled issues that relate to family inheritance. A child from a 14-18 year FGD said,

*"After a loss of my father, I stayed with my mother and we were told to stay with baba mdogo[ paternal uncle]. Most of our properties such as house furniture, shop, farm land were forcefully taken by relatives and other people, it is very sad that we could not recover our belongings [reduced tone]..."*

Participant 4: FGD 5

Episodes of losing family possessions forcefully to people who were initially known to be friends or relatives to the family were common. One female guardian reported that

*“Immediately after a loss of my husband, I have been struggling to recover our house, farm land... we owned with my husband. Shemeji na wifi zangu [brothers and sisters to her husband] came and forced me out of the house... I was threatened [deep sorrow] to be prosecuted if I had attempted to claim anything...”*

Participant 4: FGD 7

### **THEME THREE: Health outcomes**

#### **i. Improved health status**

Most of the children in both IPCF and VCT groups reported to have improved their health following an HIV test. Similar trend of information was reported in both children and adults group discussions. Children reported to have less opportunistic infection and less school interruptions after receiving an HIV test. A 16 year old child said,

*“My legs were hurt and I had a very back headache. My nose was bleeding especially...my mother brought me to PASADA and I was given treatment by [name of health care provider] and all problems went away. I am going to school and I want to be a pilot...”*

Participant 6: FGD 5

Likewise after receiving an HIV test, biological parents and guardians expressed to have less incidences associated with stigma and their children were more socially interactive to the environment compared to the times before an HIV diagnosis was made.

*“I had to go to the hospital almost every day single and it was somehow a challenge with my work... Also my son could not play with fellow because of being ill most of the time. But after joining PASADA and doctor [name of staff] helped so much and now my son comes to the hospital by himself and he goes to school and play with his fellow comfortably...”*

Participant 6: FGD 10

## **II. Recurrent illnesses**

Majority of children encountered episodes of recurrent illnesses prior to an HIV test.

Children who were cared by biological parents as compared to those cared by guardians other than biological parents were more likely to report fewer episodes of illnesses which were also less severe. One biological parent said,

*“After when I and my husband were tested HIV positive we decided to test our two children, one was found infected and the other one was not infected...”*

Participant 4: FGD 9

Recurrent illnesses were mentioned by majority of guardians as a major challenge of caring a HIV-positive child. One grandparent guardian said,

*[Name of a child] has been getting fevers, and it is usually very difficult to take him to the hospital and leave his other three siblings. I sometimes send to the hospital by himself...”*

Participant 1: FGD 10

### **iii. Summary results**

These findings demonstrate that more children were identified and enrolled in a PASADA programme after implementation of the IPCF intervention. These findings help PASADA program to realize the need for active measures to initiate children on ARV. Also children in the IPCF and VCT groups differ in their social demographics and health characteristics. Three themes related to health services, social implications and health outcomes were generated during focus group discussions and these are discussed in detail in the next section of the report.

## CHAPTER FOUR: Discussion

HIV/AIDS is still a huge problem and has caused more deaths in children than any other diseases in the sub Saharan African. Access to HIV services is still a major barrier to achieving millennium development goal number four to reduce child mortality. This research was designed to evaluate the impact of the IPCF program on identification of HIV positive children. In conducting this evaluation: we assessed the impact of IPCF in identification of HIV positive children, determined perception of the guardians on approaches for HIV identification of HIV positive children, assessed experience of living with HIV among children and their guardians and compared social and health characteristics of children in the IPCF and VCT groups. We found much younger children were identified thus a possibility of setting a better plan of care. We also found existence of many social challenges similar to what has been reported by authors in previous studies thus we recommend another study which will allow comparison of the outcomes of the IPCF intervention at PASADA and programs in different settings.

In this chapter, we discuss programmatic and policy implications from the study findings and provide recommendations in order to improve access and utilization of medical services in children living with HIV.

### **4.1. Age of children**

Children identified through IPCF intervention are much younger compared to those identified through the VCT intervention. Over 80% of HIV infections in children in Tanzania occur through vertical transmission and many of these children have been reported to miss opportunity for an HIV test (WHO, 2010) until they reach an older age. UNICEF reported poor coverage of PMTCT programme in countries such as Nigeria [3%] and Tanzania [15%], and a moderate coverage in South Africa [50%] (UNICEF, 2008). A low coverage of PMTCT services has resulted in many children being born to HIV infected mothers who never tested for HIV and never received PMTCT prophylaxis. Kellerman & Essajee (2010) have reported that it is unlikely that these children will be identified unless there is a targeted testing strategy.

A delayed diagnosis of HIV has been associated with poor health outcomes such as high rates of opportunistic infections, poor adherence to treatments and death (Wortley et al., 1995:487). The ability of the IPCF intervention to identify younger children has important implication to the national and international efforts to reducing child mortality in order to achieve the Millennium Development Goal number four (Global Health Workforce Alliance, 2010). Integration of the IPCF intervention with other traditional approaches (VCT and PICT) in systems for identification of HIV positive children would improve identification of children who are HIV positive.

#### **4.2 Approaches of HIV identification**

The overall impact on the health outcomes of children following an HIV test regardless of the approach used was good as such children and guardians reported less episodes of recurrent illnesses. The key differences between IPCF and other traditional approaches for identification of HIV positive children (VCT) and provider initiated counselling and testing for HIV is that unlike the traditional approaches, IPCF does not wait for a children to come to health facilities to initiate an HIV test and rather it tracks children when they are still at the community they live and provide links to health facilities. The IPCF involves medical and non-medical personnel provided that they work in a health facility. Unlike other traditional approaches, IPCF involves patients' relatives, visitors to health facilities, volunteers, friends of health care workers, community groups such as churches and mosques, and local government entities. The IPCF also uses unique and unspoken social attributes that exist within communities to identify those children who are at higher risk of HIV positivity. In addition, IPCF created an atmosphere that neutralized a perceived worry by health care providers of disclosing family secrets by conducting an HIV test thus health care providers, guardians and parents were actively engaged in the IPCF process. Authors have brought attention to the benefits of exploring multiple sources of support, both personal (e.g. children's friends, caregivers' peers) and institutional (e.g. schools) for addressing many challenges that limit accessibility and the use-ability of medical services by HIV positive children (WHO, 2011). In addition, WHO recommended a family-centred approach for HIV testing to ensure a maximal use of opportunities to identify HIV exposed and HIV infected children (WHO, 2010) something that features in the IPCF

intervention. In summary, the IPCF approach provides a wider scope for communities to actively participate in identifying HIV positive children and bring them to appropriate medical care. However, it is important to understand that there are similarities between IPCF and other traditional approaches in that these approaches are implemented according to the national guidelines for HIV testing which requires health care providers to obtain consent from children's parent or legal guardian and they both use same biological tests to confirm presence the infections.

Implementation of the IPCF intervention started by sensitizing the management team and health care workers of PASADA on the need for improving access to HIV testing among children and its implications to reducing child mortality. Providers were explained what is expected from them and they were allowed to ask questions on the process of implementation. Providers were requested to ask three key questions to PASADA visitors, relatives, and friends and these were referred as IPCF contacts. Prior to start of the IPCF, majority of health care providers were reluctant and had feared that the approach was going to expose children and breach confidentiality. Many providers had thought that guardians or parents of identified children were not going to accept and the process might lead to negative legal implications. Instead it turned out that the communities and families interpreted the IPCF as the way of helping children who were rather suffering and were helpless. The IPCF approach was accepted the fact that was revealed during adult and children focus group discussions. Many guardians and parents expressed their appreciations to PASADA staff that facilitated an HIV test to their children.

The research found most of HIV tests in children were preceded by episodes of recurrent illnesses in spite of multiple hospital visits, many children were still missed the opportunity for an HIV test. This finding aligns with previous reports, for instance, according to the World Health Organization (WHO) report of 2008, only 8% of HIV-exposed infants received early virological testing in 2008 (WHO, 2009). Also a study conducted in Zimbabwe to assess the effectiveness of provider initiated HIV counselling and testing showed children are identified at a very late stage of HIV disease progression (Topp et al, 2012: 1735). Analysis of international

cohort data on HIV testing in children confirmed that very few HIV infected children are started on antiretroviral therapy; and those children who receive ART are started on treatment when they are already very sick, largely due to a delay in HIV testing (Sutcliffe et al, 2008:877). Among other reasons authors have attributed to a delayed diagnosis of HIV in children include: weak health systems Kellerman & Essajee (2010) and an existence of beliefs that associate HIV and witchcraft (Allen, 2007:359).

According to the government of Tanzania, health care providers are required to initiate an HIV test for children with recurrent illnesses through the provider initiated counselling and testing for HIV. This approach should be standard and implemented in all health facilities (NACP, 2007, WHO, 2010:21). Despite provider initiated counselling and testing be a requirement, its uptake by health care providers is very minimal. Similar to this study, a study that evaluated the provider initiated counselling and testing in Zimbabwe also reported low rates of practice by health care providers and result to late identification of HIV positive being a common practice (Topp, 2012: 1735). The finding that children had attended a health facility on a number of occasions is a cause for great concern as it illustrates that health care providers are not implementing the PICT approach. This concern is also discussed later in this chapter.

The government of Tanzania recommended that by year 2012, 20% of people living with HIV who are initiated on antiretroviral treatment to constitute children (HSHSP, 2007:8). However, a progress toward achieving this expectation has shown a very minimal change. For instance, among the people who were initiated on ART in 2008 and 2009, only 7% and 8% respectively were children (NACP, 2011:13). This proportion is way below the expectations. To make this recommendation practical and obtain required results, it is important that the government of Tanzania implements strategies to ensure all HIV positive children are identified. Achieving this goal can be improved through community-based services and community involvement. A reported low rate of children on treatment is an indication of gaps in the current traditional approaches for identification of HIV positive children. In our findings, we see a direct link

between IPCF and increased rates of identification of HIV positive children enrolled in a PASADA care and treatment program.

The IPCF approach has shown the ability to identify more HIV positive children, therefore allow plan for better care for HIV positive children. When children are identified at an early age they also have reduced chance of having advanced stage of HIV disease. Besides physical illness, advanced HIV disease also has effects on development milestones of children. We consider this as a cornerstone toward achieving a universal access to ART in children living with HIV. Many authors have reported the need for examining different ways to allow identification of more HIV positive children early enough in order to increase the percentage of eligible children who are initiated on ART (Kellerman, 2010; Laufer, 2006:623). The WHO went further and made a call for nations and programmes to consider family centred approaches in order to improve access to HIV services in children (WHO, 2010).

#### **4.3. Level of education**

A difference on level of education in children identified through IPCF and VCT approaches is reported. A higher percentage of children in the VCT group reported no formal education (16%) compared to those in the IPCF group (12%) ( $P\text{-Value}=0.049$ ). We found children in the VCT group were much older compared to those in the IPCF thus are expected to have been enrolled in formal education. Children who attend formal school are expected to know more about HIV as this is part of the primary school curriculum. Also, older children are expected to be more knowledge on HIV from ongoing social marketing such as local and national HIV testing campaigns. For instance, in September 2007 the president of Tanzania his excellence Dr. Jakaya Mrisho Kikwete launched a national HIV/AIDS testing campaign aimed at ensuring universal access to HIV testing to all Tanzanian citizens. The campaign was broadcasted by newspapers, radio, television and public addressing approaches (TACAIDS, 2007). Older children and those who attend primary school were expected to have more exposure to HIV testing messages than younger children and have the potential to influence their guardians and parents to take the children for an HIV test. This study found that among children who tested HIV positive, the majority of those with formal education were found in the IPCF group and those without formal



education the majority were found in the VCT group. Lack of access to formal education has been reported as one of the social predictors of poor health outcomes in orphaned and vulnerable children (Mmbando. P, 2010:4). Looking at these findings, it implies that children in the VCT group have increased risk for future poor health outcomes contrary to the children identified through the IPCF intervention. We postulate that the IPCF intervention is protective for the future health outcomes in children. It would be important to follow these groups in future to assess the children's health outcomes.

#### **4.4. Travelling time from home to a health facility**

The research depicted that a large proportion of children in the IPCF (18%) took over three hours for travelling from home to the clinic compared to children in the VCT (12%) group. Travelling time has a very significant implication to the children's ability to access HIV testing service. Access to health services is associated with costs for bus fare, food and hospital charges. Children who reside in a further distance have increased likelihood of having limited access to HIV testing services. During our focus groups discussions we found majority of children encountered financial crisis and at some point children had to take social responsibilities and become bread winners of their families due to financial crisis encountered by their families. When access to HIV services relies on the availability of money, the children who reside at a further distance are more likely to have limited access to the services. This fact is evident in our research findings as such, majority of children in the IPCF group live in a further distance compared to those in the VCT group. It is possible that further distance had limited the majority of the children in the IPCF group their access to HIV testing services through VCT approach. Distance between child's residence and health facility precipitate other problems such as: poor adherence to treatments, lost to follow up and occurrence of recurrent opportunistic infections. According to the PASADA 2010 annual report on medical services, the centre reported that of clients who had poor adherence to ART treatment and who were lost to follow up, the majority constituted those who stayed relatively far from health facilities. It implies that children in the IPCF group would have limited access health care services.

Likewise, reports have shown that the number of HIV positive children who have access to HIV care and treatment services have remained low despite a reported improvement access among adults (Kellerman, 2010). In his study, Laufer (2006:623) highlighted the need for examining different approaches to increase access to care and treatment services in children. This is a clear indication for reviewing the current approaches (VCT and PICT) for identification of HIV positive children. Unless alternative innovative approaches are put in place to ensure all children have equal chance to accessing health care services, many children will be denied opportunities to receive an HIV test. This research shows that, through community network more HIV positive children are reached thus improve access to HIV testing among children. Involvement of medical, non-medical personnel, community health care providers, clients, hospital visitors, community recognized personnel in the IPCF approach describes it as a unique approach compared to other traditional approaches (VCT & PICT). The traditional approaches for HIV test require children to show up at health facilities. Children who fail to make it to health facilities due to distance and financial constraints are automatically excluded from being picked by the traditional approaches thus missing the opportunity for an HIV test. The IPCF approach utilizes the unique nature of African extended families which allows individuals to support each other do so particularly for the children living with HIV. Implementation of the IPCF intervention aligns with the WHO recommendation that; nations and programmes need to look for multiple accesses such as: schools, communities, friends, and peers in order to improve access to HIV testing services in children (WHO, 2011).

#### **4.5. Care givers type.**

The research revealed that more children in the IPCF group (45%) compared to the VCT group (37%) were cared by biological parents. Authors have reported biological parents being one of important barriers to diagnosis and disclosure of HIV in children. A systematic review conducted by Lori et al (2007: 156) assessed the patterns on disclosing HIV to children and reported that biological parents were reluctant to test and disclose children's status due to fear of emotional consequences associated with disclosure and disclosure of secrets of family members. The described fear of disclosing children's HIV status among biological parents in this

context may attribute to delays to diagnosing HIV in children. In the literature we see reluctance of biological parents to test their children due to the fear of disclosing their family secrets (Lori et al, 2007: 156). Our study findings contradict with the literature and show that biological parents welcomed any effort that enhanced diagnosis of HIV in their children. The research has shown that more children in the IPCF (23%) had both of their biological parents compared to only 16% in the VCT group. Among children in the IPCF group who were double orphans constituted 34% while those in the VCT group constitute 41%. These findings describe the ability of the IPCF intervention to override the barrier to diagnose HIV in children due to fears or reluctance of biological parents. This is an important finding that describes the value IPCF brings in the global efforts to improve access to HIV test in children. Delayed diagnosis of HIV in children has been associated with many poor health outcomes; therefore reluctance of biological parents to diagnosing their children is unconsciously done by the parents but presents a huge threat to the children's health outcomes. We find this character very unique and we make a recommendation for future study to evaluate the superiority of the IPCF in counteracting the effect of biological parents in delaying diagnosis of HIV in children.

#### **4.6. Loss of biological parents**

In general many children had lost one or both of their biological parents and therefore reported to have lived with at least three different relatives within a range of three to five years. These findings were consistent in the adult and children focus group discussions. The proportions of biological parents were persistently low throughout twelve rounds of adult focus group discussions. This finding confirm what is written in the literature that many children who are HIV positive are more likely to have lost one or both of their parents due to HIV and those who have lost both parents have tendency to shift between different care givers (Leyenaar, 2005:259). A loss of biological parent[s] for a child has shown to mark a critical point for that child to start experiencing physical, social, emotional and psychological challenges that affect children's wellness. Children reported episodes of recurrent illnesses and family conflicts most of times started after a loss of biological parent.

Children aged 13 to 18 years who had lost their parents at a younger age had been unprepared for the loss and many portrayed their past life as being a painful experience that lasted to a later age. Children who moved between different caregivers experienced more episodes of recurrent illness compared to children who had a permanent residence. These findings are similar to a previous research on the impact of HIV at a household level in Tanzania conducted by Urassa et al (2001:2017) which reported a 44% household mobility of family members after a death of the head of the household due to HIV. The consequences of shifting between care givers among children were not limited to interruption of continuum of medical care but also loss of medical records and loss of clarity on the children's health needs amongst care givers. During the focus group discussions, guardians particularly non- biological parents remained unfamiliar of their children's HIV status for a while until when the children were brought to health facility. Our interpretation to this phenomenon is that despite a high frequency to shift between caregivers accurate information on the children's health is never passed on or is only partially shared the fact that leads to increased episodes of treatment interruptions thus triggers episodes of recurrent illnesses. During focus group discussions of both children and guardians, features that suggested poor adherence to ARV in children with high tendency to shift were evident.

#### **4.7. Level of CD4 count**

A larger proportion of children in the IPCF group (47%) had CD4 count above 500 cells /ml compared to only 37% in the VCT group (Figure 3). We noted a difference in CD4 distribution among children in two groups as such; children in the IPCF had both low and high CD4 count contrary to those in the VCT group whose majority had low CD4 count. IPCF approach has chance to find children with high CD4 count as it gets more accepted. Currently children with low CD4 are also found because of being repeatedly missed by the traditional approaches. Previous reports have shown children are generally diagnosed at a later stage of disease progression where CD4 count is already very low (Wortley et al, 1995:487; Sutcliffe CG et al, 2008: 477; Cooke et al, 2009:9; Topp, 2012: 1735). Delayed diagnosis of HIV in children has a direct impact on the number of children who are initiated on ART. Analysis of international cohort data had confirmed that low numbers of HIV infected children who are started on

antiretroviral therapy and those who were started were already at a very late stage of disease progression mainly due to a delay in HIV testing (Sutcliffe, 2008:877).

Researchers study shows the ability of the IPCF approach to identify children with low CD4 count something that allow providers to predicts those with high risk of poor prognosis. Children when diagnosed at high CD4 count allow a better plan of care thus high chances of good health outcomes. Identification of HIV positive children at an early stage of disease progression (high CD4 count) is a critical step for programmes and nations towards making a reasonable progress in achieving the millennium development goal number four - to reduce child mortality (WHO, 2007; UNAIDS, 2004). We therefore recommend scale up of the IPCF intervention to supplement other traditional approaches for identification of HIV positive children.

#### **4.8. Health provider visits prior to an HIV test**

The research has shown that children and their guardians had multiple visits to health care providers without receiving an HIV test. Strikingly, children in the IPCF as compared to those in the VCT groups had over 4 times likelihood of visiting more than three health care providers prior to an HIV test (P-Value =0.005). This difference remained significant even after accounting for age and sex of the children. Explanation as to why children in the IPCF group than those in the VCT had made more health facility visits prior to receiving an HIV test is beyond scope of this study. However, it the information would be very useful for programmes in order to improve quality of health services in HIV positive children. It is striking that health care providers did not consider initiation of an HIV test despite clinical features suggestive of HIV as a result many children were missed the opportunity to test for HIV. The government of Tanzania requires VCT and provider initiated counselling and testing for HIV (PICT) to be implemented as a standard procedure in all levels of health facilities (NACP, 2007:3). A high magnitude of missed opportunities for an HIV test depicted by our study and many other previous studies (WHO, 2010) is a clear indication that the two traditional approaches (VCT and PICT) are not adequately implemented by health care providers. The IPCF approach assisted

PASADA to identify children from the community rather than in the health facility thus complement to the systems for identification of HIV positive children. They welcomed any initiative by health care providers that enhanced early diagnosis of HIV in children. Parents and guardians reported any initiative to enhance diagnosis of HIV in their children as life saving

It is very important for health care providers to be more vigilant in making sound clinical judgments and rule out the possibility for missing children living with HIV when children make hospital visits. Health care providers should also keep up with training that raise their awareness on HIV in order to provide sufficient attention to sick children with high index suspicion for HIV.

#### **4.9. HIV disclosure to children**

Delayed disclosure of HIV in children was prevalent across all groups IPCF and VCT. About 70% of all children remained with undisclosed HIV status for over six months following a diagnosis. Children in the IPCF group were more likely not to have been told their status compared to children in the VCT group and this difference could be explained by the fact that children in the VCT group had stayed in the programme for a much longer time than those in the IPCF group thus increasing their chance for disclosure. In addition to programmatic challenges, guardians and biological parents accounts for delayed disclosure of HIV to children. This finding suggests implementation of both VCT and IPCF need to be tailored with disclosure strategies to ensure that desirable health outcomes for children are guaranteed. Also it is critical for programs to put robust measure for HIV disclosure to children disclosure especially in situation of high influx children identified with HIV. Authors have associated HIV disclosure to children with desirable and better health outcomes (Ferris, 2007: 1088, WHO, 2011 & Wortley et al, 1995: 487). Delayed disclosure has been reported to be one of major challenges facing guardians and health care providers for children living with HIV. A study conducted by Lori et al (2007: 156) revealed that guardians and caregivers have been reluctant to conduct disclosure fearing the emotional consequences of the parents and guardians and fear of ethical obligations especially when guardians and parents started to ask providers not to use the words HIV and AIDS

#### **4.10. Age and disclosure of HIV to children**

A study conducted by Bunn in many of the African countries on the experience of children's disclosure revealed that children felt depressed and isolated if they were not given permission to talk openly about their health. This report indicated that guardians of HIV positive and cancer children were reluctant to disclose the status to their children fearing that the children would lose hope and die more quickly or would commit suicide (Bunn, 2010:3). In this study, researchers found that many children discovered their HIV status through their own initiatives at an age way below 16 years, the recommended age by the government of Tanzania for HIV disclosure to children (NACP, 2007:14). Many children were eager to know about their health and particularly in relation to their attendance to routine HIV clinics. Some children while trying to understand from their care givers and guardians as to why they had to take medications, asked questions that often did not get conclusive answers. Guardians and parents were often reported to avoid providing truthful responses by shifting the responsibility to answer the questions related to disclosure to health care providers. The fact that HIV positive children need truthful information about their health has been echoed by the WHO (WHO, 2011:10).

We found contradictions on the appropriate age for HIV disclosure to children. Various guidelines have not mentioned a specific age, others have stated school going age and others like that of Tanzania has stated age 16 years as appropriate age for disclosure. Analysis made by Lori had revealed shown that there is lack of evidence on the appropriate age for HIV disclosure in children. We propose a study to evaluate these approaches and provide recommendation based on the context. We think lack of clarity in the guidelines is also a barrier for health care providers to instigate HIV disclosure to children. During focus group discussions we conducted, we found children at aged between 7 and 13 years were capable to understand the meaning of HIV and were able to associate the status with their wellbeing. In this regard we make a recommendation for the government of Tanzania to consider 13 years as age of HIV disclosure to children. At age 13 the majority of children start to seek clarifications on issues related to their health, most of the children move from primary to secondary school the level and have a

much wider peer interaction. Also at this age majority of children encounter their first sexual debut thus clarity in their health status is critical for their own safety and for others.

#### **4.11. Access to health services**

We found a sustained increment in the number of HIV positive children identified and enrolled in PASADA clinics seven months after the IPCF intervention. Initiation of ARV in children requires series of events including: assessment of readiness of guardians, check of CD4 count, renal function, and liver function. This process may take longer than six months, however; the shorter period it takes the effective system is. It is therefore not ideal to rely on the number of children initiated on ARV and attribute this effect to the IPCF intervention due to the short study period. However, we learn that PASADA system of initiating children on ARV needs to be strengthened. IPCF also identified children with high CD4 count; therefore not qualify for ARV thus may explain the low proportion of children initiated on ARV after IPCF was implemented (Table 5). A study to assess long term health effects of IPCF which include its effect on enrolment on ARV is recommended.

In spite of a documented slight increment in the percentage of HIV positive children identified in Tanzania between 2009 and 2010, access to health services among children living with HIV is still a big problem (NACP, 2011:8). Previous studies have shown that the proportion of children who are tested for HIV represent a very small proportion of children living with HIV (UNAIDS, 2010; Laufer, 2006:623; Kellerman, 2010). In order to increase the number of children on ART, it is important for programmes to ensure that more children are tested for HIV. In this study we see an increment in the number of children initiated on ARV seven months after implementation of IPCF intervention - a finding that suggests IPCF to be an important strategy to increase number of children who are initiated on ARV. The government of Tanzania through the Tanzanian Health Sector HIV/AIDS Strategic Plan proposes that by 2012, 20% of people living with HIV who are taking ART should constitute children (HSHSP, 2007:8). The IPCF approach possesses valuable attributes that may assist the government of Tanzania to achieve this target.



#### **4.12. HIV and witchcraft**

Beliefs that associated HIV with witchcraft prevailed in both adults' and children's group discussions. Although participants did not admit to have active involvement with witchcraft practices, they described people living with HIV to associate HIV and witchcraft and to seek consultations from traditional healers in addition to consulting with biomedical providers. These findings are similar to what was reported in Sudan, a study conducted to investigate beliefs that associate HIV/AIDS and witchcraft (Allen, 2007:356). In Tanzania and many other African countries, utilization of traditional healers is a common practice. Studies have shown that over 80 percent of people in African countries consult with traditional healer before they see biomedical practitioners (Unite for Site, 2013).

Association of HIV with witchcraft has many implications on the health outcomes of PLHIV. According to the PASADA 2010 medical annual report, people with high tendency to default from ARV treatment had been associated with tendency to consult with either traditional healers or religious leaders prior to defaulting from the ARV treatments (PASADA, 2010). In addition, association of HIV/AIDS with witchcraft has a lot of economic and social implications. Many societies consider use of traditional healers as an evil or a socially unacceptable practice. This may explain why focus group discussion participants did not speak about having traditional healers. Use of traditional healers has implications and is a challenge for many PLHIV. For instance, cost associated with transportation, payment for services potential causes of drawing financial and none financial resources from families. Due to its chronic nature, HIV/AIDS itself can entice people living with HIV to seek solutions from traditional healers in order to obtain solutions of their illness. Consequently while seeking consultations from traditional healers; people are delaying undertaking HIV tests. For children in particularly, where decisions rely on the ability of guardians or parents to take the children for medical care, the process may take a much longer time hence high risk of poor health outcomes. The time that is spent seeking help from traditional healers by people living with HIV who are already taking ARV also poses a huge barrier for the PLHIV to meet the care and treatment requirements for follow up. These

findings indicate that it is important for programmes that offer HIV services to integrate specific services that allow involvement of traditional healers to partnership with biomedical practitioners in offering HIV services.

#### **4.13. Legal Support**

Many barriers in accessing legal support existed among parents and guardians of HIV positive children. Single female parents were mostly affected. It appears that especially when a woman loses her partner, a lot of family conflicts emerge that can even result in violence among family members. The findings from the focus group discussions revealed a high tendency of losing family possessions forcefully to people who were initially known to be friends or relatives to the family. This experience was common among female single parents. It was very hard for the victims to defend their rights and the belongings due to lack of knowledge and funds. Participants lacked understanding of traditional laws of inheritance which limited the ability for social networks such as relatives and friends to provide appropriate support. In some cases participants reported to have stopped making follow up simply because of discouragement from relatives of a lost partner. In addition to women being the most affected people, children were also impacted directly by the practices. These findings are similar to the report by (Tamar, 2011) that Tanzania lack equality in law of inheritance that has resulted to sufferings among widows and orphaned children. In this report, women particular have been reported to lose their properties, being evicted from their homes under witchcraft accusations and sometimes lose their children by abusive relatives.

Effects of events of losing family possessions forcefully do not only affect the physical wellness but also the children's emotional and spiritual wellness. Children expressed difficulties to cope with abrupt changes in the life style they lived when they had all parents to an ordinary or low living standard. Children who go through this transition with no psychological support are more likely to end up deprived in their mental wellness in the future.

#### **4.14. Challenges of living with HIV positive children with guardians**

Stigma and discrimination were often mentioned as one of major challenges of living with HIV positive children. Compared to other guardians, single parents were more likely to experience discrimination from their surrounding networks. Denials of social and psychological support from family members were the key indicators findings and we interpret these as important indicators of stigma and discrimination. We found that household mobility of children between different caregivers especially after a loss of biological parent was a common practice. However, most of the times children had moved to their uncle or aunt as a first caregiver following loss of biological parents and grandparents became the last in the list. A very unique difference was depicted when children were cared by guardians other than biological parents compared to the children cared by grandparents. The latter group had a much reduced reported episodes of stigma and discrimination. Our analysis suggests that grandparents present a much better living environment for orphaned children compared to non-biological caregivers. Researchers attribute this unique characteristic of grandparents to the fact that grandparents are more attached to the grandchildren through the loss of their own children. We propose in future a study to assess short and long term health effects in children cared for by grandparents versus those who are cared by other than biological parents.

Many other challenges of caring for HIV positive children were depicted these include: financial constraints, lack of nutritional supplements for ill children, limited time to keep up with hospital follow up requirements. Despite the positive attributes of the grandparents depicted by the study, one major challenge is on their physical abilities to meet the children's demands due to their age. Many of the grandparents had physical disabilities such as blindness (secondary to cataracts), body weakness (secondary to stroke), back pain and lack of strength which in turn limited their ability to provide optimal care to their grandchildren. As a result many children took social responsibilities at a very young age and therefore denied the opportunity to grow while celebrating their childhood. For instance, those who assumed responsibilities of being bread winners of the households had to refrain from going to school or interrupted hospital scheduled appointments.

Traditionally children are required to attend monthly HIV clinic regardless of their clinical condition. Considering the above prevailing limitations, it is critical for programme managers and policy makers to review the requirements for children to visit their HIV clinic on monthly basis. Those who are stable on medication could have a longer duration between clinic visits. We also recommend a system shift from a provider centred to a family centred care to allow more members of the community to share the burden of caring HIV positive children.

#### **4.15. Discussion Summary**

The research evaluation has revealed that IPCF intervention has impact on the younger children through enabling early detection of HIV infection. Through the intervention, we saw more children identified and were subsequently linked to care and treatment programme. Characteristically, majority of children in the IPCF group had higher CD4, travelled longer distance to the clinics, had multiple hospital visits prior to an HIV test compared to children in the VCT group. The research has revealed that provider initiated and counselling and testing is yet to be fully implemented according to the national guidelines for HIV counselling and testing and on the other hand the approach for voluntary and counselling for HIV has number of inadequacies particularly in reaching all children who are in need for an HIV test. Disclosure of HIV to children is still a huge problem that requires involvement of parents, guardians, children and health care providers. We also learned that the majority of the children who are double orphans assume broader social responsibilities which hinder their ability to access various social services such as schools and medical care. Also stigma and discrimination prevail in the community and are important barriers to improve quality and access to HIV services in children.

#### **4.16. Limitation of the study**

The study could not obtain information on the number of children who were tested for HIV regardless of their HIV status as this data was not captured during implementation of the IPCF. Design of the IPCF had focused on service provision and less as a research therefore, the programme kept data for children who were tested HIV positive. For future developments, we

recommend IPCF programme to keep records of children reached by the intervention by the intervention to allow assessment of the effectiveness and efficiency of the intervention. Also this is a cross sectional study; therefore we lack information of the long term health outcomes of the two interventions IPCF and VCT such as: initiation of ART, TB episodes and mortality. However, researchers employed both qualitative and quantitative methods in obtaining and analysing the data and this is a major strength of the study that allowed a better understanding of relationships between variables we studied. The IPCF study was conducted in a single unit “PASADA” as there were no other facilities that implemented the IPCF intervention. PASADA has 10 outlet facilities placed in a varying social and environmental context. The study enrolled children from all ten service outlets canters to allow generalizability of the study findings. Also involvement of external experts during data collection and analysis phases of the research were used to minimize information bias from research team.

## CHAPTER FIVE: Conclusion and recommendations

### 5.1. Conclusion:

The study objectives was to assess the impact of the IPCF intervention on identification of HIV positive children, compare characteristics of children identified through IPCF and VCT intervention, determine the perception of the guardians on the approaches for identification of HIV positive children, and examine the experience of living with HIV among children living with HIV and guardians of HIV positive children.

We found that IPCF intervention has impact on the younger children through enabling early detection of HIV. A sustained increase in the number of children enrolled in a PASADA care and treatment programme was found after initiation of the IPCF intervention, therefore the IPCF intervention has important values to supplement strategies to increase number of children with access to HIV testing and thus those who are initiated on ARV.

We compared characteristics of children identified through IPCF and VCT and found that children in the IPCF group were much younger, visited multiple health facilities prior to an HIV test, and are more likely to have formal education compared to children in the VCT group.

Also the majority of children in the IPCF reside at a further distance from HIV clinics compared to those in the VCT group thus hinder their ability to access HIV testing services. We also found more children in the IPCF group were cared by biological parents compared to those in the VCT group and that IPCF override the possibilities of biological parents to act as barriers of diagnosis and disclosure of HIV in children. Delayed disclosure of HIV to children was common among all children in the IPCF and VCT groups and it is one of major challenges of caring children living with HIV. Regarding CD4 count, majority of children in the IPCF had higher CD4 count while the majority in the VCT group had predominantly low CD4 count, indicating that children in the IPCF have higher chance for good health outcomes compared to those in the VCT group. No difference was noted between two groups on parental status, and nature of primary care

givers. Both groups of children had significant health improvement in their health and social outcomes after receiving an HIV test and starting on ART.

Studying the perception of guardians on the approaches of identification of HIV positive children, most of the guardians welcomed any initiative that enhanced immediate HIV test for children. Guardians were frustrated by tendency of health care providers to delay HIV tests. We found distinction between IPCF and VCT approaches as such, in the IPCF, children are identified while they are still at the community they live and there is active involvement of families, communities, and health care providers. Those who tested for HIV through IPCF reported the approach as friendly and “lifesaving”. Many guardians and biological parents missed the opportunity to test their children and resulted to delayed HIV diagnosis. We learned that PICT is rarely practiced by health care providers according to the nation guidelines. This is of great concern and it indicates that there must be additional methods of sensitising HCPs to the need to test children for HIV.

Assessing the experience of living with HIV among HIV positive children and their guardians we learned that stigma and discrimination due to HIV prevail at the family and community levels and are among major barriers to improving health outcomes of HIV positive children. Many children had lost one or both of their biological parents and frequencies to shift between care givers were high. The consequences of shifting between care givers include: interruption in the continuum of medical care, loss of medical records, and loss of clarity on the children’s health needs amongst care givers. Many physical, social, emotional, and psychological challenges of living with HIV positive children were evident mostly after a loss of children’s biological parents.

The study found that beliefs that associated HIV with witchcraft and tendency for PLHIV to consult with traditional healers while consulting with biomedical practitioners was a prevalent practice. We found existence of barriers to accessing legal support that existed among parents and guardians of HIV positive children. Also children lack psychosocial supports that allow them to cope with the changes from a full life with both biological parents to being an orphan. Other

challenges of caring HIV positive children reported by guardians include: financial constraints, lack of nutritional supplements for ill children, and limited time to keep up with hospital visits.

## **5.2. Recommendations**

We recommend implementation of the IPCF intervention by the Tanzanian ministry of health and social welfare.

We recommend that HIV testing strategies include programmes for HIV disclosure to children. The IPCF intervention enabled systems to identify more children from the community and children were linked thus, scale up of the IPCF intervention is an important stride to achieving millennium development goal IV to reducing child mortality.

Due to delayed diagnosis and missed opportunity for an HIV test, we recommend that health care providers become more vigilant in making sound clinical judgments and take the opportunity to test children when they present. Also health care providers need to keep up with training that raise their awareness on HIV in children in order to provide sufficient attention to sick children with high index suspicion for HIV.

We recommend a discussion about another age for HIV disclosure to children in Tanzania. Currently disclosure is recommended at age 16 years. We also recommend a study to evaluate the significance of specifying age for HIV disclosure to children versus leaving it open for health care providers to decide when to disclose HIV status is paramount.

Orphaned children who were cared by grandparents had shown reduced episodes of stigma and discrimination at a family level compared to the children who were cared by non-grandparents caregivers. In this regard, we propose a study to assess short and long term health effects among children cared for by grandparents versus those who are cared by other than biological parents.



Due to high tendency of communities to associate HIV with witchcraft and PLHIV seek consultation from traditional healers prior to consulting with biomedical practitioners, we recommend care and treatment programmes to consider a mutual collaboration with traditional healers in order to improve health outcomes of PLHIV. We also recommend programmes that offer legal and psychosocial support for families to be tailored with care and treatment programmes.

Traditionally children living with HIV are required to attend HIV clinics on monthly basis regardless of their clinical condition. We recommend a system change to extend time intervals between clinic visits for children who are stable on ARV medications.

The study revealed that the burden of caring children living with HIV is a heavy burden for parents and guardians especially when health systems limit active involvement of communities to provide optimal health care for the children. We therefore recommend a system shift from provider centred care to a family centred care approach to ensure the burden of caring children living with HIV is shared across families and communities with appropriate support.

Due to lack of information on the number of children who were reached by the IPCF and tested for HIV, we recommend a follow up study to gather all information regardless of the children HIV status to allow fully assessment of the efficacy of the interventions IPCF, VCT and PICT.

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## APPENDICES

### Appendix I: Participants information sheet

#### **Participant's information sheet**

Evaluation of the Paediatric HIV Intensified Case Finding (PICF), PASADA's strategy of identifying HIV positive children and linking them to HIV testing services and appropriate medical care.

You are invited to take part in a research project to evaluate pediatrics HIV intensified case finding, PASADA's approach to identifying HIV positive children in the community.

I would like to thank you for your time and efforts to understand our study. This discussion will take approximately 30 minutes.

The information sheet summarizes the contents of the study that you may wish to take part in. For you to decide whether or not you agree or disagree to be part of this study, you will be provided with adequate time to ask questions to any of the health care providers and research team. Room for questions will still remain open even after this short discussion. Questions can be direct or by using the telephone numbers provided at the end of this sheet.

Again I would like to thank you for your time, please take time to make your decision.

#### **i. What is the purpose of the study?**

We want to evaluate the pediatric HIV intensified case finding (PICF), a PASADA initiative to reduce the burden of HIV in children.

#### **ii. Is it a must for me to take part of this study?**

No, this is not a must. You may agree or disagree to be part of this study. Whatever your decision, YES or NO, it will not have any effect on the care you are receiving from our centers. On agreeing to take part in this study, you will be asked to sign a consent form to justify your decision. In whichever case, you are free to change your decision and withdraw at any point with or without giving reasons. This will not affect the care you are receiving from us. You are welcome to take time in making a decision by sharing this information with any of your health care providers, the research team, friends or family members.



**iii. What are the contents of this study if I become part of it?**

The section reads as follow; a member of our research team will speak to you and your child on the approach used to identify your child's HIV status. The study will have two phases that require your participation. In phase one of the study, you and your child will separately have a chance of being invited to participate in a group discussion. The group will have 8 to 12 members who will present with similar status as that of yours of caring a HIV positive child. The discussion will base on you and your child's life experience that relates to the child's health before and after being identified to have HIV. This phase will take 45 to 60 minutes. In phase two, the child will be interviewed and asked demographic and social information which is considered to have influence on the child's health. Phase two is expected to take 15 to 20 minutes. This information is prepared for you to keep as a reminder of the aim of the study.

**iv. Am I going to acquire any benefit from participating?**

There is no direct benefit to participants; however participants may find very useful information when discussing the questionnaire with care providers and during focus group discussions. Participants will have the opportunity to experience the way in which other people are managing to overcome the challenges of living with HIV. The anticipated benefit is to verify whether the PICF has useful elements that may reduce the burden of HIV in children and in the community in general.

**v. Are there any risks to me if I take part in the study?**

This will depend on the degree of tolerance of individual participants. Some participants may become emotionally upset. The research team is prepared to handle any situation of this nature appropriately if it happens.

**vi. Will my involvement in the study be kept confidential?**

Information which will be collected in this study will be kept confidential. Efforts will be made so that no one may identify you. Whatever information you are going to provide will be kept separate from your personal information (for example your name and personal address). The research team will use numbers or codes and not your names. There will be no access to your information from anyone outside the study.

**vii. Will I get the results of the study?**

At the end of the study, the report will be sent to the care and treatment center where you access your medical care.

**viii. Who is the main organizer of the research?**

The following are people who you can contact for any information with regards to the research:

Questions about the study:

*Dr. Frank Manase, PASADA: Tel +255-754-383896*

*Email-fmanase@yahoo.com*

Any ethical questions or human right issues about the study:  
*Muhimbili University of Health and Allied Sciences Ethics Committee:*  
Professor Eligius Lyamuya,  
Ethics Committee Director,  
Telephone: +255-754-495933

## Appendix II: Consent form for children and adults (in Swahili)

### **a. Guardián.**

1. I ..... (name) declare to have understood the purpose of the research and that I am not going to gain any financial benefit from my decision to participate in the study.
2. I had sufficient time to ask questions and that I can withdraw from the study at any time without any form of penalt.
3. I give consent to participate in the study.

Name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

Research assistant: Signature \_\_\_\_\_ Date: \_\_\_\_\_

Witnes

Health care provider or guardian

Signature \_\_\_\_\_

Date: \_\_\_\_\_

### **b. Child.**

#### **Children assent form.**

1. I ....., have understood the contents of the study and agreed to participate together with my guardian  
(Name).....who is my  
.....,
2. I do understand that I am free to agree or disagree with sharing information at any point of the study without affecting the privilege I have of accessing PASADA health care services.
3. I agree to participate in this study.

i. Signature of the child.....

ii. Researcher Name.....

iii. Researcher signature.....

iv. Date.....

### Appendix III: Focus group discussion guide

#### **Focus group discussion guide.**

**Mark X ---PICT [ ]      Normal VCT [ ]**

- ❖ The discussion will have groups of eight to twelve children.
  - ❖ The group discussion facilitator will initiate and maintain discussion using the following guiding questions:
    1. How were things in your life before you came to PASADA?
    2. How did you come to hear about PASADA?
    3. How are things now that you are in the PASADA?
    4. How does being HIV-positive affect your life?
    5. What is your opinion on the approach used to identify your HIV status?

#### Appendix IV: Questionnaire

Name of research assistant.....  
Work station (Name of the facility).....  
Registration number.....  
CTC Number.....  
**Location**  
District.....Ward.....  
Physical address (Explain).....  
**Sex** Male [ ] Female [ ]  
**Age** ..... [Years]  
**Parental status;** Two parents [ ] Single parent [ ] No parents [ ]  
If orphaned state at what age did the child lose his/her parents.  
Father.....Years, Mother.....Years

1. What is your level of education
  - a. No formal education [ ]
  - b. Not complete primary level of education [ ]
  - c. Primary education [ ]
  - d. Secondary Education [ ]
  - e. Not Complete Secondary education [ ]
2. What is the average time you spend from your home until when you reach PASADA facility for health care service.
  - a. Less than 2 hours [ ]
  - b. 2 to 4 hours [ ]
  - c. Above 4 hours [ ] Write number in hrs.....
3. Describe relationship with your primary care giver.
  - a. Biological parent [ ]
  - b. Aunt [ ]
  - c. Uncle [ ]
  - d. Family friend [ ]
  - e. Good Samaritan [ ]
  - f. Step parents [ ]
  - g. None of the above [ ] Explain.....

4. At what age the child joined PASADA? .....Years
  
5. Name relation of the person accompanied you during your HIV test
  - a. Biological parent [ ]
  - b. Aunt [ ]
  - c. Uncle [ ]
  - d. Family friend [ ]
  - e. Good Samaritan [ ]
  - f. Step parents [ ]
  - g. None of the above [ ] Explain.....
  
6. How many health facilities you visited seeking appropriate health care before joining PASADA?
  - a. None
  - b. One
  - c. Two
  - d. Three
  - e. More than three [state].....
  
7. What approach was used to identify the child's HIV status identified?
  - a. Voluntary counseling and testing (VCT) [ ]
  - b. Provider initiated counseling and testing (PICT) [ ]
  - c. Pediatric intensified case finding (IPCF) [ ]
  
8. How long did it take from testing to disclosure of child's HIV status?
  - a. Less than three months [ ]
  - b. Four to six months [ ]
  - c. Over six months [ ] Mention (Months).....
  
9. Was the child linked to any of the following services?
  - a. HBC [ ]
  - b. Special pediatric clinic [ ]
  - c. OVC services [ ]
  - d. Others [ ] Explain.....
  
10. Was the approach used to identify HIV status of the child associated with stigma ?
  - a. No [ ]
  - b. Yes [ ]

If yes give explanation.....

(Ask question 10 and 11 at the end of interview where the child will be assessed to determine whether she/he needs extra help to assist sharing of this information. This can be more privacy or any form of help from other children).
  
11. Is there a time in your life you would consider being mistreated/Abused?
  - a. Yes [ ] if yes go to number 5 and 6

b. No [ ]

12. In which way have you have been mistreated/abused? (More than one answer is acceptable)

a. Physical abuse [ ]

b. Emotional abuse [ ]

c. Sexual abuse [ ]

d. Negligence [ ]

e. Chose not to say [ ]

f. Others [ ] Mention.....

**To be referred to the clinical notes.**

13. What was the child's first CD4 count (% for <6years and absolute value for >6 years.

.....

14. What was the child's first WHO clinical staging

a. Stage one [ ]

b. Stage two [ ]

c. Stage three [ ]

d. Stage four [ ]

e. Not known [ ]

15. Is the child taking ARV?

a. Yes [ ]

b. No [ ]

16. What was the child's initial diagnosis for opportunistic infections

a. Malnutrition [ ]

b. Tuberculosis [ ]

c. Skin Condition [ ]

d. Chest condition [ ]

e. Gastro intestinal condition [ ]

f. Others [ ] Mention.....

17. What was the initial body weight of the child when enrolled to PASADA.....(Kg)

Appendix V: Permission to conduct research at PASADA institute, a research site.

Dar es salaam, 24th August 2010

Dr. Frank Manase  
BOX 70255  
Dar es Salaam

Dear Dr. Manase,

**RE: Permission to conduct the study entitled "Evaluation of Pediatric Intensified  
Case Finding – PASADA's approach to reducing the burden of HIV in children,  
Dar es salaam Tanzania" at PASADA**

Reference is made to the above heading.

I am hereby pleased to inform you that permission to conduct this study at PASADA's facility is granted. You may proceed with all other necessary arrangements.

Yours sincerely,

signature removed

Mary Ash  
(Executive Director)





**Appendix VI: Ethical clearance: Tanzania National Institute of Medical Research**



THE UNITED REPUBLIC OF  
TANZANIA



National Institute for Medical Research  
P.O. Box 9653  
Dar es Salaam  
Tel: 255 22 2121400/390  
Fax: 255 22 2121380/2121360  
E-mail: [headquarters@nimr.or.tz](mailto:headquarters@nimr.or.tz)  
NIMR/HQ/R.8a/Vol. IX/1147

Ministry of Health and Social Welfare  
P.O. Box 9083  
Dar es Salaam  
Tel: 255 22 2120262-7  
Fax: 255 22 2110986

27<sup>th</sup> May 2011

Dr Frank Manase  
PASADA  
P O Box 70255,  
DAR ES SALAAM

**CLEARANCE CERTIFICATE FOR CONDUCTING  
MEDICAL RESEARCH IN TANZANIA**

This is to certify that the research entitled: Evaluation of pediatric HIV intensified case finding-PASADA approach in reducing burden of HIV in children Dar es Salaam, Tanzania (Manase F *et al*), has been granted ethics clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is submitted to the Ministry of Health and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health & Social Welfare and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine. NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Approval is for one year: 27<sup>th</sup> May 2011 to 26<sup>th</sup> May 2012.

Name: Dr Mwelecele N Malecela

Name: Dr Deo M Mtasiwa

Signature Signature removed

Signature Signature removed

CHAIRPERSON  
MEDICAL RESEARCH  
COORDINATING COMMITTEE

CHIEF MEDICAL OFFICER  
MINISTRY OF HEALTH, SOCIAL  
WELFARE

CC: RMO  
DMO

## Appendix VI: Ethical approval UCT



UNIVERSITY OF CAPE TOWN

Health Sciences Faculty  
Research Ethics Committee  
Room E52-24 Groote Schuur Hospital Old Main Building  
Observatory 7925  
Telephone [021] 406 6626 • Facsimile [021] 406 6411  
e-mail: lamees.emjedi@uct.ac.za

30 September 2010

HREC REF: 363/2010

**Dr F Manase**  
Public Health & Family Medicine  
Falmouth Building  
Medical School

Dear Dr Manase

**PROJECT TITLE: EVALUATION OF PAEDIATRIC HIV INTENSIFIED CASE FINDING-PASADA APPROACH IN REDUCING BURDEN OF HIV IN CHILDREN IN DAR ES SALAAM, TANZANIA 2010**

Thank you for submitting your new study to the Faculty of Health Sciences Human Research Ethics Committee.

Thank you for carefully and comprehensively addressing our queries.

**Approval is granted for one year until 15 October 2011.**

Please send us an annual progress report (website form FHS 016) if your research continues beyond the approval period. Alternatively, please send us a brief summary of your findings so that we can close the research file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

**Please quote the REC. REF in all your correspondence.**

lamees

Yours sincerely

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, HSE HUMAN ETHICS**

Signature removed



Federal Wide Assurance Number: FWA00001637.  
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

kenjedi

Appendix VII: IPCF identification coupon

<b>TAARIFA YA MLEZI/MZAZI</b>		
Makazi.....	Wilaya.....	Kitongoji.....
Jina la Balozi.....Simu ya Balozi.....		
	<b>TAARIFA YA MTOTO</b> <b>IDARA YA TIBA</b> P.O. BOX 70225 MOBILE: +255 718 197663 FAX: +255 222 8666 18	<b>No.</b> 3538  Tarehe: .....20.....
	Jina.....Umri.....Jinsia ..... Makazi.....Wilaya.....Kitongoji..... Jina.....Jina maarufu.....Simu.....	
<b>TAARIFA YA MLEZI/MZAZI</b>		
Makazi.....	Wilaya.....	Kitongoji.....
Jina la Balozi.....Simu ya Balozi.....		
	<b>TAARIFA YA MTOTO</b> <b>IDARA YA TIBA</b> P.O. BOX 70225 MOBILE: +255 718 197663 FAX: +255 222 8666 18	<b>No.</b> 3539  Tarehe: .....20.....
	Jina.....Umri.....Jinsia ..... Makazi.....Wilaya.....Kitongoji..... Jina.....Jina maarufu.....Simu.....	

# Appendix VIII: Supplement figures

Figure 5. Number of health facilities visited by children prior to an HIV test by Approach (IPCF vs VCT)

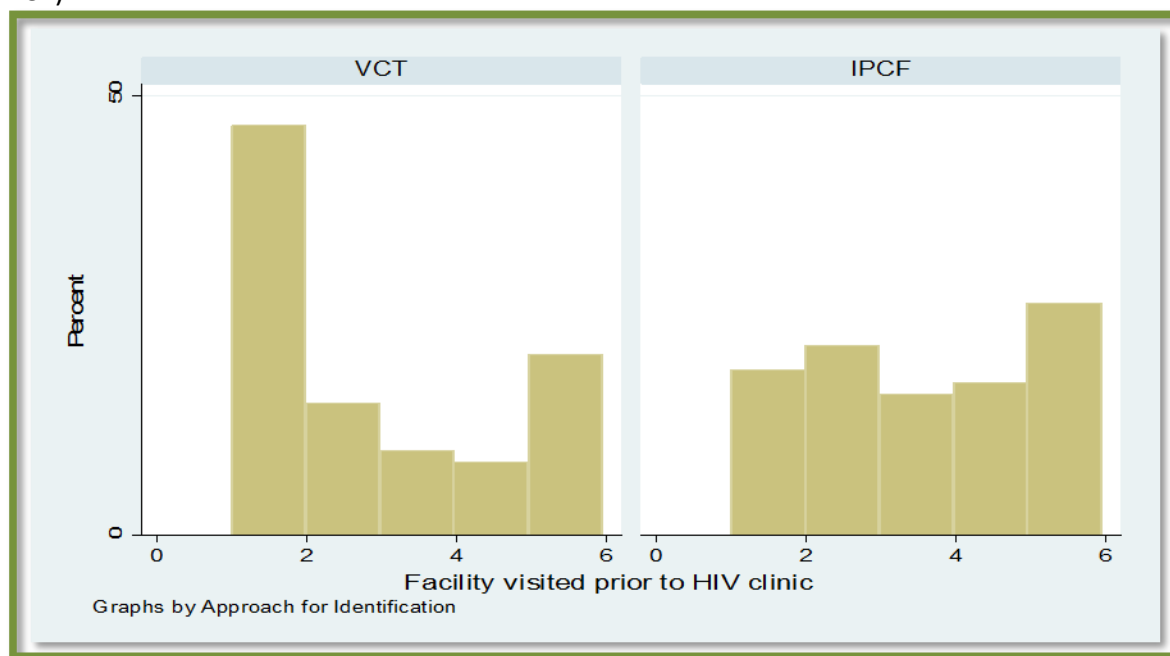


Figure 6. Age at which an HIV test was performed by Approach (IPCF vs VCT)

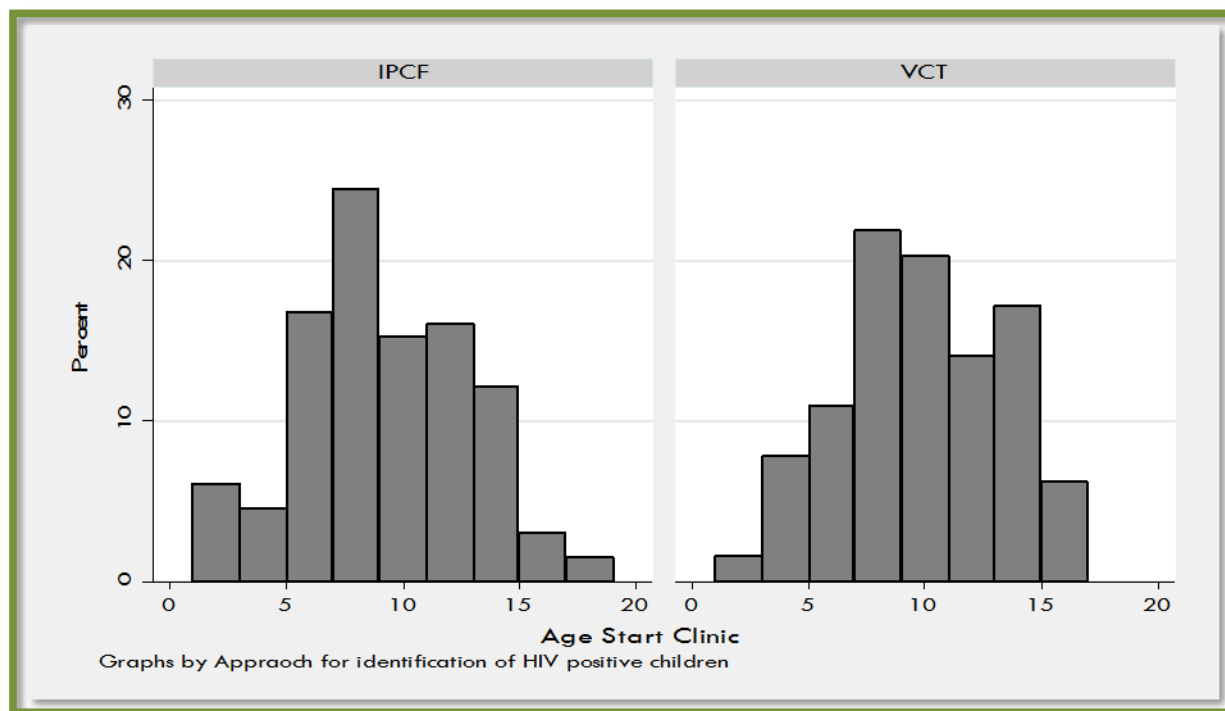


Figure 7. Age of children by Approach (IPCF vs VCT)

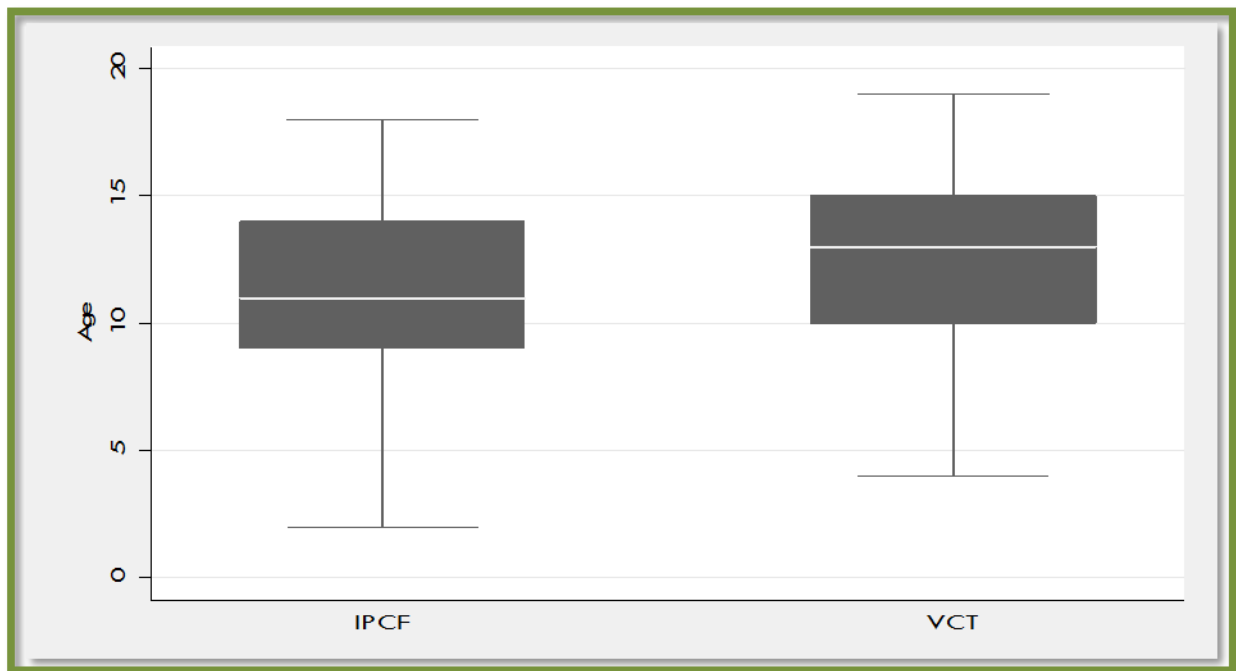


Figure 8. Number of children initiated on anti-retroviral treatments by period (Before Vs After)

